

**CHALLENGES AND MANAGING MECHANISMS OF HA-MPHAPHULI HOME-
BASED CAREGIVERS FOR PATIENTS LIVING WITH HIV/AIDS IN VHEMBE
DISTRICT, LIMPOPO PROVINCE**

BY

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SCIENCES OF THE UNIVERSITY OF VENDA IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF THE MASTER OF PUBLIC
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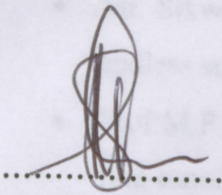
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DECLARATION

I, **MOTSEI MPHO SOLOMON** hereby declare that the dissertation for the degree of Master of Public Management at University of Venda hereby submitted by me has not been previously submitted for a degree at this or any other university. This is my own work in design and execution, and that all reference materials contained therein has been duly acknowledged.



Signature

08/05/2014

Date

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On my personal note, I dedicate this project to my parents, Mr. Modikeng Emmanuel Motsei and Mrs Nkopane Rose Motsei. You were there for me all the way.

Managing mechanisms of Home-Based caregivers for patients living with HIV/AIDS in Vhembe District, Limpopo Province. Finally, concrete propositions were developed for the implementation of quality community and home based care programmes in Vhembe district. HIV/AIDS is a global challenge and its impact is evident. This places a burden on hospitals and health professionals. To ease this burden there are home-based care programmes which, through home-based caregivers provide patients living with HIV/AIDS with physical and palliative care. However, these HBCGs face various challenges such as poverty, discrimination and stigma when caring for PALHIV, and their own emotional strain, which becomes burdensome without sufficient support from the home-based care centre.

The study uses both quantitative and qualitative techniques for data collection and analysis. Qualitative techniques were mostly used in that they provide the researcher with the understanding of experiences and problems faced by Home Based Care Givers. Random and purposive samplings were used for the selection of sample for the study. Both primary and secondary data were used for analysis in this study. Secondary data were obtained from government publication, research publication, and report. Primary data were obtained through questionnaires. Data was gathered through questionnaires, categorised into themes and analysed. Major findings revealed that social challenges faced by HBCGs include poverty, stigmatisation and discrimination. Emotions experienced by HBCGs include guilt, anger, hopelessness, but they have spiritual reliance through prayer as one of their coping mechanisms.

Findings revealed that the majority of the participants were concerned that they were living with HIV and AIDS. Most of them expressed anxiety, worries and fears of death. Another majority complained about the burden of opportunistic infections. Almost half of the participants felt guilty bringing misery to their families and complained of stigma and discrimination. However, a minority group of participants felt that to live with HIV and AIDS is not the end of life. Relatives were mentioned as the main care providers to HIV and AIDS patients. However, they were also

ABSTRACT

The purpose of this study was to describe the challenges and managing mechanisms of Hamphaphuli Home-Based caregivers for patients living with HIV/AIDS in Vhembe District, Limpopo Province. Finally; concrete propositions were developed for the implementation of quality community and home based care programmes in Vhembe district. HIV/AIDS is a global challenge and its impact is evident. This places a burden on hospitals and health professionals. To ease this burden there are home-based care programmes which, through home-based caregivers provide patients living with HIV/AIDS with physical and palliative care. However, these HBCGs face various challenges such as poverty, discrimination and stigma when caring for PALHIV, and their own emotional strain, which becomes burdensome without sufficient support from the home-based care centre.

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cited high as a source of stigma. Conclusions were made that women and girls are at the highest risk as they bear the burden of care.

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LIST OF ACRONYM

AIDS	Acquired Immune Deficiency Syndrome
CHBC	Community Home-Based Care
CHBCGs	Community Home-Based Caregivers
CBOs	Community-Based Organisations
FBOs	Faith-Based Organisations
HBC	Home-Based Care
HBCC	Home-Based Care Centre
HBCGs	Home-Based Caregivers
ICBC	Integrated Community-Based Care
HIV	Human Immunodeficiency virus
NGOs	Non- Governmental Organisations
PALHIV	Patients living with HIV
WHO	World Health Organization

CHAPTER 1: ORIENTATION OF THE STUDY

1.1 Introduction

The increasing incidence of human immune virus (HIV), Acquired Immune Deficiency Syndrome (AIDS) and Tuberculosis (TB) is putting a lot of strain on the health services in many developing countries, including South Africa. The HIV and AIDS incidence has added a burden of complexity to health system across the globe (Floyd & Wilkinson 2000). As 80 percent of South African population makes use of the public sector for their health needs, increase work loads on the health system are a cause for concern (Steinberg et al 2000).

According to the UNAIDS Global report (2006) 5.5 million people were living with HIV at the end of 2006 in South Africa. In Sub-Saharan Africa an estimated 4.3 million people infected with HIV and AIDS need home-based care but only 12 percent receive it. Many governments, including that of South Africa, encourage volunteers to become involved in community health workers' programmes to care for those infected and affected by HIV and AIDS (UNAIDS 2006).

As many households in South Africa are affected by HIV and AIDS, there is a growing need for assistance with care and support. Increasingly households are faced with the needs of sick family members which include assistance with daily living, treatment and palliative care. Approximately 90 percent of AIDS care takes place in the home and care is mostly given by women and girls. Given the limitation on availability of formal inpatient programmes, households rely upon informal caregivers (for example, household or family member, friends, community members or voluntary organizations) and home-based care programmes for assistance (UNAIDS 2006).

Home and community-based care (HCBC) has been practiced throughout the ages. Care of homes was provided mostly by women and initially only for their family members. In fact, ancient Hebrew nurses participated in planned visitation programmes of sick people in their homes (Dolan, 1978:15). During the first century of the Christian Church, deaconesses provided care at home. They were called visiting nurses and were the forerunners of community health nursing of which home-based care forms a part (Dolan, 1978:45).

St Francis de Sales was instrumental in the establishment of a voluntary organization which visited the sick in their homes. Consisting of women these organizations dressed patient's wounds and performed basic physical and household care (Dolan, 1978:91). This thread can be traced throughout history and is still evident today in most countries, including North America and Europe (Uys & Cameron 2003:3). It has taken different forms in different countries based on the availability of resource, cultural issues and context. Due mainly to the inability of the health care system to meet the ever-increasing demand for services to the chronically ill and disabled, the need has once again arisen for HCBC. This has been exacerbated by the advent of the HIV/AIDS epidemic and the increasing aged population (Health and Development Networks, 2001:13).

The Department of Health (DOH) (2001:1) defines home care as "the provision of health services by both formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death". Home care is a comprehensive service and includes preventive, promotive, therapeutic, and rehabilitative, long-term maintenance and palliative care (DOH 2001:4; Van Dyk 2005:260). Initially formally introduced to the health sector in this district. The roles and responsibilities of all the role players, particularly the caregivers and nurses, were not clarified. Dealings with current HBC carers and nurses found that, in some instances, health professionals view the service with suspicion in terms of quality of service provide and the possibility that this category of health worker, home-based carer, may take over their work, as many carers do aspire to become health workers. For HCBC to be effective and to provide a quality service

provided to the community, it was decided that clarity regarding care-givers' roles should be given. This study will focus on the operational challenges faced by home-based care-givers in dealing with HIV/AIDS. Home-based care givers in ward 24 of Thulamela Municipality will be the respondents in this study.

1.2 Background of study

According to the Older Person Act, 2006 (Act No. 13 of 2006), Section 11 (1) (a)(ii) stipulates that the Minister any, in collaboration with any relevant Minister of Member of the Executive Council in a province develop a home based care, which ensures that a frail older person receives maximum care within the community through a comprehensive range of integrated services.

A few decades ago, a disease, previously unknown to the human race, began to kill people in alarming and terrifying circumstances. The disease is now known as Acquired Immune Deficiency Syndrome (AIDS), which is caused by Human Immunodeficiency Virus (HIV). The first recognized cases of HIV and AIDS occurred in America in 1981 when very rare forms of pneumonia and a rare skin cancer, suddenly appeared simultaneously in several patients (Van Dyk, 2001:5)

Southern Africa remains the region worst affected by the HIV and AIDS epidemic. Combinations of contributory factors have been identified; These include, poverty and social instability, high levels of sexually transmitted infections, the low status of women, sexual violence, high labour mobility (migrant labours), and lack of good governance in many countries. South Africa has the sixth highest prevalence of HIV in the world, with 18.8 percent of the population estimated to be infected. The HIV and AIDS global report, estimated that 320 000 people died of AIDS-related deaths in South Africa during 2005 (UNAIDS 2006:23).

The increase in HIV and AIDS prevalence across the country has posed a serious strain on caregivers for AIDS patients as caring for someone with AIDS can substantially increase the workload of a caregiver

Many theories about the origin of AIDS have been postulated. They range from a belief that the virus was developed as an instrument of biological warfare to a view that the virus is being used by aliens from outer space to kill the people of planet earth. Now it is generally accepted by scientists that HIV crossed the species barrier from primates to humans at some time during the 20th century (Van Dyk, 2001:6)

The HIV/AIDS epidemic is a major threat to social and economic development in South Africa. It is severely impacting on the developmental gains made since 1994 especially with respect to improvement of the quality of life and services rendered to families and children. Services that are in high demand include psychosocial support, material assistance in the form of food parcels, social relief to the distress, burial grants, as well as foster care and child support grants.

In Southern Africa caregivers reported stressors that are related to HIV disease such as risk of contagion; stigma and feeling of helplessness. Although HIV can be treated, it is currently an incurable disease. Caregivers were also confronted with inadequate medical resources while experiencing repeated exposure to death, profound grief, loss and ethical dilemmas (Hendrick 2001 and Baer & Longo 1989). According to Grossman and Silverstein (1993) social workers, nurses, counselors, caregivers and other health care professionals who work with people infected and affected by HIV and AIDS experience burnout from the excessive demands on their energy, strength and resources. Silverman (1993) raised the possibility of HIV caregiver's stress syndrome, noting that there was a relative lack of attention paid to the stresses experienced by providers of care for persons with HIV and AIDS.

The escalating HIV/AIDS epidemic has increased the need for home care and resulted in a more programmatic approach (WHO 200a:8). According to the National HIV and

Syphilis Antenatal Sero-Prevalence Survey in South Africa 2006, in Limpopo, the rate decreased from 29,5% to 29,0% (DOH 2006:13). It was noted, however, that the prevalence rate in the Capricorn district rose from 22.2% in 2005 to 24,2% in 2006. This resulted in an increase of AIDS-related conditions requiring care and support. The inadequate number of medical, nursing and allied health professionals in the public sector, the cost of institutional care, and overcrowding of hospitals compounded the problem. The DOH (2001:1) has built on the groundwork done by non profit organizations, scaling up and formalizing the programme through the development of guidelines and a training course.

As indicated earlier, community members originally initiated HCBC to assist family and community members in need. Consequently, the care provided was basic and limited to the skills that carers had and was not guided by professional nurses. Thus, community professional nurses were initially excluded and may not have been aware of the importance of their role. This exclusion may have resulted in a lack of cohesion and coordination between carers and professional nurses as well as the quality of care not being articulated.

Home care is a fragile, new field in South Africa requiring support and standardization so as to ensure quality care (Van Dyk 2005:260). Therefore management is essential to ensure the provision of quality care. The professional nurse, as the health professional and team leader with the competence to identify needs and develop plans accordingly, must control the quality.

1.3 Statement of the problem

Health facilities are experiencing difficulties partly due to an increase in the number of HIV and AIDS cases. As a result, patients are turned away from hospitals due to limited beds in Ha-Mphego village. Households and communities are assuming responsibility for the care of people living with HIV and AIDS. However, there is concern about the communities' readiness to provide the care (Van Dyk, 2008:332)

Community/home-based care is a fairly recent phenomenon in South Africa. Historically, funding and other resources were allocated for preventative interventions. The increasing numbers of people with acute HIV infections have made AIDS more visible and various programs designed to counter this phenomenon have emerged. Unfortunately due to the limited amount of resources available, viz. funding, human resources and material goods, many home-based care givers are ill-equipped to provide quality care services. Although some challenges are common across geographical areas, it is always important to carry out location-specific research so as to generate properly targeted interventions. Thus, this study will explore and describe the challenges home-based care givers in ward 24 of Thulamela municipality, Vhembe District of Limpopo Province face in dealing with HIV and AIDS.

The overall objective of the health services is to develop a health delivery system that is proactively responsive to the prevailing needs and problems a health care delivery system that addresses the current and foreseeable health, disease and health care management problems by focusing on the provision of a minimum package of essential health services to the people of Vhembe district with the emphasis on the poor, women and children. According to the Department of Health, Programme of Work, the health status of Vhembe district is challenged by important social and environmental factors:

- Low levels of education and literacy, particularly among women
- Frequent outbreaks of cholera, dysentery and other communicable diseases
- Limited supplies of clean, safe drinking water in some areas
- Widespread poverty with almost half the population living on less than \$1 a day
- Regional disparities in access to and consumption of health services

HBCGs have difficulty in dealing with all the challenges, which makes them, feel emotionally as well as socially weak and hamper their performance. In general they face challenges that are emotional, financial, physical and social in nature.

1.4 Aim of the study

The overall aim of the study is to investigate the challenges and managing mechanisms of Ha-Mphaphuli Home-Based caregivers for patients living with HIV/AIDS in Vhembe District, Limpopo Province

1.5 Specific Objectives

- To investigate the challenges experienced by Home-Based Caregivers (HBCGs) in giving Home-Based Care (HBC) to Patients living with HIV
- To investigate the kind of support provided to HBCGs in giving HBC to (Patients living with HIV) PALHIV and
- To explore the coping mechanisms that can be used by HBCGs in giving HBC to Patients living with HIV;

1.6 Research Questions

- What are the challenges experienced by Home-Based Caregivers (HBCGs) in giving Home-Based Care (HBC) to Patients living with HIV?
- What are the kind of support provided to HBCGs in giving HBC to (Patients living with HIV) PALHIV?
- What are the coping mechanisms used by HBCGs in giving HBC to Patients living with HIV?

1.7 Significance of the Study

The study comes at a time when different strategies of dealing with HIV and AIDS are being tried and home-based care is one of them. Home-based givers face numerous challenges in their day to day work. This study will contribute to the body of knowledge on HIV and AIDS. The results will be useful when developing strategies to address the challenges that home-based givers face. The findings would provide direction for further

investigation as only limited research has been done on home-based care. The findings would also assist policy-makers to develop policies to address identified issues. Finally, community members would also benefit from the study, as better understanding would result in improved service delivery.

1.8 Delimitations of the Study

The present study was delimited in the Home based care at Ha-Mphego Village which fall under in Ha-Mphaphuli Tribal Authority. The study will be confined to the challenges facing home-based care givers in the areas serviced by Tshilidzini Hospital.

1.9 Limitations of the Study

Funds were a limiting factor as the study required a lot of funds for travelling, typing, binding and photocopying. Due to the sensitivity of the topic, some people may feel uncomfortable to answer the research questions because they are not sure where the information will be taken to. It is anticipated that some people might be reluctant to participate in the study. Lastly, although the results obtained in this study might apply to other areas, this is a case study and the results should never be generalized. The findings of this study have identified and recognized the following as limitations: The sample size in this study was small; the results cannot be generalized to other situations and the findings can only be suggestive and Time was too limited for the researcher to be able to gain enough trust of the research participants, which made it difficult to obtain more in-depth information.

1.10 Definitions of concepts

For the purposes of this study, the following terms will be used as defined below:

HIV: This is an acronym for Human Immunodeficiency Virus. This virus only affects human beings (Corne, Jones & Powell, 1993:6)

Community-based organization (CBO)

AIDS: It is short for Acquired Immune Deficiency Syndrome, which is acquired because the disease is not inherited. Human Immuno Deficiency Virus which enters the body from outside causes the disease. It is a collection of many different conditions that manifest in the body (or specific parts of the body) because when HIV has weakened the body's immune system it cannot fight the disease-causing agents that are constantly attacking it. Therefore AIDS must be regarded as a syndrome of opportunistic diseases, infections and certain cancers that can kill the infected person in the final stages of the disease (Van Dyk, 2008:4).

CD4 count: In this study CD4 count is understood in accordance with ACASA (2003)

Home-Based Care: Home-based care is the care given in the home of a person living with HIV and AIDS. Usually, a family member or friend (the primary care giver), provides the care and is supported by a trained community caregiver. In ideal circumstances a multi- disciplinary team supports family and community caregivers so that they can meet the specific needs of the individual and family. The team consists of all the people involved in care and support, and may include a medical practitioner or professional nurse, a social worker or trained counselor, a pastor or spiritual leader, volunteers, a traditional healer, friends and neighbours, and community members (Van Dyk, 2008:332).

ORIENTATION OF THE STUDY

This chapter provides a clear picture of the focus of the study. A brief study background,

Chronic illness: According to Fox and Fama (1996:10) illness that typically has a fluctuating and unpredictable course with exacerbations and improvements is regarded as chronic. For purposes of this study, chronic illnesses refer to those illnesses that cannot be cured, rather they can only be controlled, for example, AIDS.

This chapter will demonstrate the magnitude of HIV and AIDS, principles and goals of

Community-based care (CBC): CBC is the care that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, and encourages traditional community life" (Van Dyk 2005:262).

This chapter deals with a systematic discussion of types of research and choices for the study purpose. The practicality of the research methods and design are included in the discussion.

Community-based organization (CBO)

A CBO is an organization situated at community level and addressing community identified needs at this level.

PALHIV: Patients living with HIV are people who have tested positive for HIV and are living with the virus. In this study PALHIV are in different phases of HIV infection. Some are taking treatment because of the decline of their CD4 count whereas some are still recovering and others are fully recovered and self reliant.

CD4 count: In this study CD4 count is understood in accordance with ACASA (2003) namely that it is a blood test that measures the number of T4 (CD4 cells) in one's blood. It tells one how the immune system is and how much damage the HIV virus has done to the immune system. As the disease progresses T4 count becomes lower. When CD4 count is somewhere between 350 and 200, PALHIV must start taking treatment. These are the PALHIV that this study focuses on.

1.11 Organisation of the Study

CHAPTER 1: ORIENTATION OF THE STUDY

This chapter provides a clear picture of the focus of the study. A brief study background, problem statement, hypothesis, research objectives and purpose of the study are also presented in this chapter.

CHAPTER 2: LITERATURE REVIEW

This chapter will demonstrate the magnitude of HIV and AIDS, principles and goals of home-based care, as well as the activities and scope of home based care givers.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

This chapter deals with a systematic discussion of types of research and choices for the study purpose. The practicality of the research methods and design are included in the discussion.

CHAPTER 4: DATA PRESENTATION, ANALYSIS AND INTERPRETATION

Data is presented, analyzed and interpreted in this chapter.

2.1 Introduction

CHAPTER 5: CONCLUSION, FINDINGS AND RECOMMENDATIONS

This chapter presented the conclusion, findings of the study as well as the recommendations for future research.

The argument a researcher is making to justify his or her own study. According to Merriam and Mackinnon (2004:23), literature review is an existing published works that are most closely related to the research topic.

A literature review is a systematic process whereby a search is performed to determine the existing body of knowledge relating to the proposed topic under study (Gough-Lindsay 2004:2). The purpose of a literature review is "to determine the extent to which the topic under study is covered by the existing body of knowledge" (Babbie & Mouton 2002:55).

2.1 Caregivers in Vhembe District

Crosby (2008:1) defines a caregiver as anyone who provides help to another person in need. There are various descriptions given of various types of caregivers, which differ from country to country and from institution to institution. Different scholars use different names to define them such as carers, caregivers, community caregivers, health workers and home-based caregivers. All these different names in essence carry the same description as the one mentioned by Crosby. The difference may only be the location of the patient, for example, at home or at a hospice. Some of the caregivers are unpaid, unacknowledged for and undervalued, despite their contribution.

Many caregivers are poor, have large families or are living with HIV themselves and are thereby increasing their susceptibility to the virus, which contributes to their difficulties in coping with their work. Donors provide financial contributions towards communities, who are the implementers of home-based programmes through HBCGs who provide care

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Babbie and Baxter (2004:427) define literature review as a summary of what is already known on a given topic, relevant to the argument a researcher is making to justify his or her own study. According to Merigan and Huston (2004:23), literature review is on existing published works that are most closely related to the research topic.

A literature review is a systematic process whereby a search is performed to determine the existing body of knowledge relating to the proposed topic under study (Ganga-Limando 2004:2). The purpose of a literature review is “to determine the extent to which the topic under study is covered in the existing body of knowledge” (Babbie & Mouton 2002:55).

2.2 Caregivers in Vhembe District

Greene (2008:1) defines a caregiver as anyone who provides help to another person in need. There are various descriptions given of various types of caregivers, which differ from country to country and from institution to institution. Different scholars use different names to define them such as carers, caregivers, community caregivers, health workers and home-based caregivers. All these different names in essence carry the same description as the one mentioned by Greene. The difference may only be the location of the patient, for example, at home or at a hospice. Some of the caregivers are unpaid, unaccounted for and undervalued, despite their contribution.

Many caregivers are poor, have large families or are living with HIV themselves and are thereby increasing their susceptibility to the virus, which contributes to their difficulties in coping with their work. Donors provide financial contributions towards communities, who are the implementers of home-based programmes through HBCGs who provide care

to PALHIV to mitigate the impact of HIV/AIDS (France 2008:1; Jackson 2002:250). A distinction between two main types of caregivers should be highlighted for the purposes of this study, namely formal and informal caregivers (Primo 2007:20).

Formal caregivers include professionals and specialists such as physicians, pharmacists, medical social workers, occupational and speech therapists, doctors and nurses. This category of caregivers also includes trained volunteers, spiritual volunteers, spiritual counsellors associated with AIDS service organisations, AIDS care teams and hospice programmes.

Informal caregivers comprise relatives, spouses or partners and friends who provide at-home care on an unpaid basis. They are in some cases not trained at all, or have received very little training. Respected traditional healers in various communities, especially in sub-Saharan Africa, also provide care for PALHIV. This study, which focuses on CHBCGs, refers to the former category, namely formal caregivers.

2.3 Legal, ethical and policy issues

No more complex challenge could ever have been devised to test our moral fibre than HIV/AIDS. The pandemic has given rise to a vast array of ethical, moral and legal issues, many of them previously unknown. Caregivers and counsellors in the HIV/AIDS field must heed the national policies, laws and guidelines relevant to their work. Knowledge and guidelines is required to advise and assist clients who may be unfairly discriminated against (Van Dyk, 2008:429).

The South African Constitution (Act 108 of 1996) is the supreme law of the country and all other laws must comply with its provisions. The constitution includes a bill of rights which lists basic human rights that apply to all citizens and therefore also to people living with HIV/AIDS. Under no circumstances should people living with HIV/AIDS be discriminated against on the grounds of their HIV/AIDS status.

People living with HIV or AIDS have the same basic rights and responsibilities as all other citizens. The charter of Rights on AIDS and HIV which was launched in 1992 is the Bill of Rights of people living with HIV or AIDS. The human rights principles in the Charter are essential to ensure non-discrimination and provide public health in South Africa. People living with HIV or AIDS have the same rights to liberty and autonomy, security of the person and freedom of movement and right to confidentiality as all others (Van Dyk, 2008:430).

2.4 Roles and responsibilities of HBCGs

HBCGs see the reality of HIV/AIDS in their area of work and yet strive to ensure that infected and affected people can live with hope and dignity to face the challenge of living with the epidemic, from the time of infection to their eventual death. This is done through provision of medical, emotional and physical support to PALHIV and their families, including sustainable relations in the community. They also provide psycho-social support to the families of PALHIV (France 2008:1; Sardiwalla 2004:2).

2.4.1 Physical care

HBCGs provide basic nursing care and comfort measures such as symptom recognition, diagnosis, treatment, symptom management, referral and follow up. Basic nursing care include positioning and mobility, bathing, wound cleaning, skin care, oral hygiene, adequate ventilation, and guidance and support for adequate nutrition. They furthermore identify situations where adequate caregiving such as basic needs of shelter, food, bedding and clothes is not provided (WHO 2002:35).

2.4.2 Palliative care

HBCGs also provide palliative care, which involves a combination of active and compassionate long-term therapies intended to comfort and support individuals and families living with a life threatening illness. The HBCGs strive to meet the physical,

psychological, social and spiritual needs of PALHIV, a task that requires a team approach and that includes the patient, family, health and social welfare workers as well as the HBCG (WHO 2002:36).

They also assist PALHIV with running of errands, recreational services, companionship, transportation, in-patient services, clerical work, conference participation, public speaking, and counselling among other duties, to lighten the burden of the disease on the client and family. They also accompany the patient to the hospital to obtain medical treatment and negotiate for what they perceive as appropriate treatment based on their experience (France 2008:1; Jackson 2007:22; Makoae & Jubber 2008:41; Sardiwalla 2004:3; WHO 2002). In a survey of home-based care patients in Malawi, about 15% of PALHIV were healthy and not showing visible signs of HIV. More than one third needed help bathing and walking, and about 28% needed help going to the toilet. In another study in South Africa about 16-17% of PALHIV could not control their bladder or bowels, and needed help getting on and off the toilet.

A similar proportion required help in bathing themselves. Given the debilitating effect of HIV/AIDS, a certain percentage of PALHIV may need assistance performing the simple tasks that most of us take for granted, and they are often assisted by HBCGs. These are some of the roles and responsibilities HBCGs have to perform under dire circumstances, for example, where there is poor sanitation. In a South African survey it was found that less than half of the households had a tap and only 20% of rural homes had access to a flush toilet, with a quarter having no access to any form of toilet or latrine (Leake 2009:2), which does not make roles and responsibilities any easier. All these factors make it difficult for the HBCGs to optimally fulfil their roles and responsibilities.

According to Jackson (2002:249), the role of caring for PALHIV is very difficult, even to the point where a caregiver may end up feeling a sense of failure, inadequacy, resentment and anger, which will be discussed under section 2.10 below. The care role is made more difficult by the fact that PALHIV may get sick, recover, become ill with something else, and again recover, and so on. This could be an endless, confusing circle which can be

emotionally exhausting to both the caregiver and the patient. In summary, the roles and responsibilities of HBCGs are to provide basic care and assistance deemed necessary by the conditions of the client. The support HBCGs provide varies widely and depends on the needs and availability of resources.

2.5 Challenges faced by HBCGs

HBCGs are faced by many challenges emanating from caring for PALHIV. Caring for PALHIV is associated with high levels of stress, burnout, anxiety, and financial burden, and can be very draining physically, emotionally and psychologically as well as socially. Both caregivers and PALHIV are faced with challenges such as continuous physical and psychological deterioration, their own mortality and the fear of contagion and death. This can challenge a caregiver's ability to cope. If they do not learn how to care for themselves, they will not survive the onslaught of the HIV pandemic (Akintola 2004:23; Van Dyk 2001:282).

2.5.1 Stress and burnout

According to Van Dyk (2001:283), burnout can be defined as a syndrome of physical and emotional exhaustion involving the development of a negative self-concept, negative job attitudes, and loss of concern and feeling for clients. According to Gueritault-Chalvin et al. (2000:149), occupational burnout may occur where work demands especially those of an interpersonal nature lead to chronic emotional exhaustion, depersonalization and a reduced sense of personal accomplishment, such as may happen when caring for PALHIV.

HBCGs work very closely with PALHIV who are dying and this can leave them emotionally and physically drained. According to Ross, Greenfield and Bennet, (1999:729), emotional overload brings unhappiness, over-involvement, exposure to others' grief, death of a client and a feeling of helplessness on the part of the caregiver.

When HBCGs feel emotionally stressed they therefore face work related stress, which leaves them very susceptible to symptoms of burnout such as loss of interest in and commitment to work, a lack of job satisfaction, not being punctual and neglecting duties, a loss of sensitivity in dealing with clients or patients, referring to clients in a dehumanized or purely impersonal way, avoidance of clients to limit the time spent with them and frequently but unnecessarily referring clients to other health care professionals, deteriorating relationships with colleagues and friends, tension and distress in their personal life as well as difficulties in getting on with people. These symptoms can lead to a high level of turnover, absenteeism, and reduced productivity, which impact on the general running of the organisation (Jackson 2002:253; Pendukeni 2004:14; WHO 2002:420).

When HBCGs begin to feel that they are not supported, it often leads to burnout. If burnout is not controlled it may lead to depression, which will make them feel despondent and will affect the caregiver's ability to provide optimal care to PALHIV. Depression in the context of HIV is caused by many factors including a feeling of a lack of control over one's fate, changes in a person's self-image, and exposure to stigma. (Simpson 2006:8; Uys & Cameron 2003; WHO 2002:40).

A study by Demmer (2004:524) provided evidence that younger caregivers for PALHIV are more likely to experience burnout than older workers. This may be due to lack of experience as well as to being over-involved in the job. There is no significant difference in burnout based on marital status and sexual orientation in HIV caregiving or a person's occupational role.

The following has been found in different African countries: a study in Zambia reported that, despite the fact that health workers were still relatively motivated, emotional exhaustion occurred among 62% of the respondents who took part in the study (Dieleman, Biemba, Mphuka, Schinga-Sichali, Sissolak, Van der Kwaak et al. 2007:1). In one Namibian study, mentioned in Pendukeni (2004:14), it was found that nurses were

not prepared to deal with PALHIV, and as a result looked for reasons to stay away from work clearly confirming that stress leads to absenteeism.

Workload also contributes to burnout. According to the study conducted by Dieleman et al. (2007:1) in Zambia, HIV/AIDS has had a negative impact on the workload of carers and has considerably changed or added tasks to an already overburdened health sector. Gueritault-Chalvin et al.'s (2000:158) research reported that the perceived workload was positively correlated to burnout, and even significantly predicted burnout. Stress leads to frustration as a result of HBCGs' lack of knowledge and skills in dealing with patients, work demand, lack of competence, and as a result also of their hiding their true feelings, emotions and fear. This could be as a result of a lack of training or understanding in respect of professional conduct and accountability, indicating a need to strengthen monitoring and supervision of the HBCGs (Jackson 2007:76; Pendukeni 2004:14).

According to WHO (2002:71), a HBCG from Namibia, described the stress they undergo as carers and their ways of dealing with such stress in the following manner, I think of our work like holding up a candle of hope to other people. But unless we protect that candle, it will burn out. This shows that certain HBCGs recognise that they need to care for themselves lest they burn out. According to Primo (2007:22), caregiver stress can be divided into primary and secondary stress. Primary stress comes from the everyday duties of a caregiver such as assisting a patient with bathing, toileting and managing the patient's difficult behaviour as well as the planning of daily care. Secondary stress emanates from the caregiver's conflict with other family members (own family or the family of the patient).

Stress and burnout affect caregivers providing care to patients suffering from various chronic diseases such as cancer and dementia. When considering whether AIDS caregivers experience more burnout than those caring for patients with other chronic diseases, contradictory results are reported. According to Gueritault-Chalvin et al. (2000:150), research on cancer showed that other caregivers experienced similar stress-producing activities as AIDS caregivers. There was no difference in the level of burnout

experienced by both cancer and AIDS caregivers. On the contrary, Demmer (2004) highlighted that in countries such as Germany and Italy, the caregivers of PALHIV were more prone to burnout than caregivers working in fields such as oncology. According to Gueritault-Chalvin et al. (2000:158), more research on burnout indicated that health workers who have more concentrated exposure to HIV/AIDS may be more likely to experience burnout.

2.5.2 Physical effects

According to Primo (2007:22), caregiving is burdensome and may compromise a caregiver's health. Symptoms of poor physical health are markedly present among AIDS caregivers and are associated with care-related demands and stressors.

The level of depression among caregivers strongly correlates with different physical ailments. The multiple tasks they perform often result in neglecting their own self-care, such as nutrition, exercise, socialising and sleep. They develop detrimental health behaviour such as overeating, smoking, not exercising and disturbed sleep patterns (they sleep less than non-caregivers). Consequent to detrimental health behaviour, certain caregivers, especially women, gain weight, their immune system weakens and the healing of their wounds are often affected. One study mentioned by Leake (2009) found that most caregivers suffered physically as a result of caring and experience headaches, body aches, backaches and exhaustion as common problems.

2.5.3 Financial aspects

In a study by Jackson (2007:76), finance was one of the challenges experienced by HBCGs as their stipend included transport to see a doctor, and transporting patients to hospital, for example. Some therefore leave caregiving after having received training, as they often do not receive any stipend or it is not sufficient to cover their needs and those of their patients. This challenge can be categorised as secondary stressors (economic hardships), which may include loss of employment and income, as highlighted in Primo (2007:22).

2.5.4 Stigma and discrimination

According to Van Dyk (2001:284), and Friedland, Renwick and McColl (1996:16), both infected and uninfected HBCGs working in the HIV/AIDS arena are stigmatised. According to WHO (2002:40), for PALHIV and their family members, the stigma, fear and discrimination often associated with the illness can create barriers to effective care. This was reported in a study mentioned in a WHO report, which revealed isolation, fear and discrimination as common themes that were related to HIV/AIDS. The study also acknowledged that teaching health and social service personnel about universal precautions is not sufficient to reduce stigma behaviour (WHO 2002:49). HBCGs on the other hand are at times avoided or ostracised because they work with PALHIV, and therefore they are deprived of much needed support.

Stigmatisation amongst colleagues working with PALHIV is another challenge faced by HBCGs. Research indicates that employers and employees often discriminate against workers who are suspected to be or confirmed to be HIV-positive. This behaviour emanates from ignorance about the facts around HIV transmission and the progression of the disease, fear by employers or superiors of reduction in productivity and profits, as well as fear of stigmatisation of the organisation in the event that clients get to know workers are positive (Pendukeni 2004:17). There is still a lot to do to change the attitudes of people towards PALHIV.

2.5.5 Attachment

According to Bennett, Ross and Sunderland (1996:145), many HIV carers expressed fear of getting too involved or attached to their patients and forming close relationships with them. They try to avoid closeness because of the imminent death of the PALHIV.

2.5.6 Risk of contracting the disease

Many studies, such as Primo (2007:23), Pendukeni (2004:12) and Dieleman et al. (2007:23) have identified contagion as one of the serious concerns among HBGC. One major stress producing concern shared by many AIDS workers is anxiety over safety practices and fear of occupational contagion, rooted in occupational exposures to HIV. According to a study conducted by Pendukeni (2004:11), the nurses in her study expressed fear of contagion not only from the PALHIV but also from their colleagues, as is well described by one the respondents: I am scared of getting the HIV virus not only from the patients but from colleagues as well. I know I cannot contract it from sharing cups, and so on, but some colleagues have open wounds and some oozing rushes from the lips and all over the face.

This fear is exacerbated by the difficulties experienced in maintaining consistent and appropriate infection control precautions. HBGCs may also harbour irrational fears of contagion taking place through casual contact, or touching utensils used by a PALHIV, despite their knowledge of the facts about HIV/AIDS. This fear can consequently cause physical or empathetic withdrawal from persons with HIV/AIDS, resulting in deprivation of physical and emotional contact with the PALHIV, which is the most valuable intervention.

In another study of caregivers in Zambia, more than 75% of the respondents expressed fear of infection in the workplace, despite the fact that there are protective measures in place (Dieleman et al. 2007:1). According to Leake (2009:5), close contact with patients faeces, vomit and other bodily fluids create the risk of HIV and tuberculosis infection for the caregiver. The risk is exacerbated by not taking precautionary measures such as wearing rubber gloves. However, even though there are anecdotal reports of caregivers becoming infected with HIV in this manner, there is little documented evidence of this (Gueritault-Chalvin et al. 2000:150; Pendukeni 2004:18; Primo 2007:25).

In a study by Demmer (2004:526) it was found that there was a higher score on burnout among the HBCGs who experienced fear of contagion as well as those feeling discomfort in dealing with injection drug users and PALHIV (unfortunately this article by Demmer does not state clearly as to where the study was conducted).

2.5.7 Confidentiality and autonomy

Confidentiality is one of the challenges faced by HBCGs. According to Makoae and Jubber (2008:37), confidentiality has mainly been considered from the perspective of protection of PALHIV from stigmatisation; however, this contradicts the fundamental values of shared responsibility in informing other sexual partner/s so that they can practise safe sex (WHO 2002:48). WHO (2002:42) mentions that some PALHIV do not want their families, including their spouses or sexual partners, to know their diagnosis and the HBCGs should agree to this as it is the human rights of the patients. This is evident in the study by Primo (2007:25), which reported that HBCGs are often designated as the keepers of secrets. The keeping of secrets not only depletes emotional energy and causes inner conflict and isolation, but also affects the ability to provide a professional relationship.

Some patients cared for by HBCGs present obvious symptoms of opportunistic infections but refuse to test for HIV, and the HBCGs cannot force them. All these ethical dilemmas, together with a lack of appropriate community resources and facilities, can make a HBCG in the field of HIV/AIDS experience a sense of inadequacy and exacerbate their difficulty in coping with their work (Primo 2007:26).

2.5.8 Human sexuality

According to Primo (2007:24), HBCGs struggle with discussions on issues of sexuality with PALHIV, especially because HIV/AIDS is contracted sexually. This discomfort that HBCGs suffer can lead to inadequate sexual history recording, which is necessary for diagnosis and treatment of the PALHIV. The lack of information makes it difficult for the

caregiver to respond adequately to the needs of the patient, thereby compromising the quality of care that the patient can receive.

2.5.9 Workload

Health professionals can no longer provide adequate care to patients in public hospitals due to the workload, which is exacerbated by staff absenteeism, attrition resulting from resignations and HIV/AIDS-related deaths. At a time when the efficient staffing levels of the workforce are compromised by HIV, the demand for HBCGs' services continues to rise, especially from PALHIV. This section has highlighted different types of challenges that HBCGs go through as they provide care to PALHIV. Delays and difficulty in dealing with these challenges can affect the quality of care that they provide to PALHIV.

2.6 Social support of Home Based Care Givers (HBCGs)

Care giving takes an enormous physical, psychological and economic toll on its providers, for they have to deal with multiple deaths of their patients, as mentioned in Uys and Cameron (2003:23). They therefore need more access to psycho-social support and economic assistance to help them sustain this physically and emotionally draining, yet vitally important service. However, providing emotional support is very difficult for HBCGs if they do not feel supported them (WHO 2002:40).

Without support they may experience burnout and it will be difficult for them to give compassionate care (Uys & Cameron 2003:28). It is therefore important that caregivers should become proactive and try to guard against potential stressors that could lead to difficulty in coping with work. According to Jackson (2002:250), caregivers need to know when to seek professional help, and to have access to spiritual and counseling support to help them and the patient cope emotionally. A professional relationship in the workplace is also documented to reduce stress at work, therefore enabling coping (Pendukeni 2004:16).

Primo (2007:29) points out that through talking, sharing feelings or releasing them through crying, laughing, dancing together with other caregivers as they have the same work demands, can help one to cope better with feelings such as isolation, anger, sadness or grief. Social workers are able to connect to caregivers so that they can form spiritual and counselling support groups. The caregiver's mental and physical health is vital to the PALHIV, making it critical that the caregiver must be able to strike a balance between taking care of him-/herself first, so as to be able to take care of other people. This can be done through rest and exercise, enough sleep and eating well.

According to WHO (2002:49), the HBCGs need to be provided with an opportunity to express their fear, uncertainties and prejudices provided by the organisation they work for. The organisation must ensure that the environment is conducive for the HBCGs to express themselves. In this way they can overcome negative emotions and learn more about the experiences and challenges facing PALHIV. A study by Dieleman et al. (2007:1) reported that organisational support for caregivers to deal with HIV/AIDS was either haphazardly employed or not in place at all. Demmer (2004:525), in his article on health care workers, mentions that it is important for the caregivers to feel that their organisation or institution is supportive, that it values their contributions and cares about their well-being, listens to their complaints, helps them with their work-related problems and treats them fairly.

Less organisational support, including a lack of support from supervisors and colleagues, is linked to burnout. Support can be in the form of clear policy guidelines, standards and regulations to govern the HBCGs (Jackson 2007:23), and which are well understood by the HBCGs. These can be well understood if the HBCGs themselves become part of the process of their development. Adequate resources such as staff, education, equipment and finance need to be made available to ensure successful implementation of such policies and guidelines (Uys & Cameron 2003:23).

This emphasises that staff support by the employer may reduce the stress and burnout experienced by caregivers for PALHIV (Pendukeni 2004:16). The more support gained,

the more PALHIV begin to open up to others and thereby learn to cope more efficiently and gain more strength and wisdom through the support of others. Recognition and reward from supervisors are known to act as buffers against stressors.

2.7 Magnitude of HIV and AIDS

Approximately 30.8 million adults and 2 million children were living with HIV at the end of 2007 (UNAIDS, 2008). During 2007, some 2.7 million people became infected with the human immunodeficiency virus (HIV), which causes AIDS. The year also saw 2 million deaths from AIDS a high global total, despite antiretroviral (ARV) therapy, which should reduced AIDS-related death among those who received it. The number of deaths probably peaked around 2005, and has since declined only slightly. The overwhelming majority of people with HIV, some 95% of the global total, live in the developing world. The proportion is set to grow even further as infection rates continue to rise in countries where poverty, poor health care systems and limited resources for prevention and care fuel the spread of the virus.

Globally, around 11% of HIV infections are among babies who acquire the virus from their mothers: 10% result from injecting drugs; 5-10% is due to sex between men; and 5-10% occurs in health care setting. Around half of the people who acquire HIV become infected before they turn 25 and typically die of the life threatening illness called AIDS before their 35th birthday. By the end of 2007, the epidemic had left behind 15 million AIDS orphans, defined as those aged under 18 who have lost one or both parents to AIDS. These orphans are vulnerable to poverty, exploitation and themselves becoming infected with HIV. They are often forced to leave the education system and find work, and sometimes to care for younger siblings or head a family (UNAIDS 2008).

In 2007, around 37,000 children aged 14 or younger became infected with HIV. Over 90% of newly infected children are babies to HIV-positive women, who acquire the virus during pregnancy, labour or delivery, or through their mother's breast milk. Almost nine-tenths of such transmissions occur in sub-Saharan Africa. Africa's lead in mother-to child

transmission of HIV is firmer than ever despite the evidence that HIV ultimately impairs women's fertility: once infected, women can be expected to bear 20% fewer children than she otherwise would. Drugs are available to minimize the dangers of mother-to child HIV transmission, but these are still often not reaching the places where they are most needed. The area in Africa south of the Sahara desert, known as sub-Saharan Africa, is by far the worst-affected in the world by the AIDS epidemic. The region has just over 10% of the world's population, but is home to 67% of all people living with HIV. An estimated 1.9 million adults and children became infected with HIV during 2007. This brought the total number of people living with HIV/AIDS in the region to 22 million by the end of the year. HIV prevalence varies considerably across this region-ranging from less than 1% in Madagascar to over 25% in Swaziland (UNAIDS, 2008:23).

In sub-Saharan Africa, AIDS killed approximately 1.5 million people in 2007. Average survival in the absence of treatment is around 10 years after infection. ARV drugs can dramatically extend survival, allowing many years of healthy life, but these drugs remain unavailable to most Africans. Unlike women in most other regions in the world, African women are considerably more likely at least 1.4 times to be infected with HIV than men. There are a number of reasons why female prevalence is higher than male in this region, including the greater efficiency of male-to female HIV transmission through sex and the younger age at initial infection for women (UNAIDS, 2008:34)

HIV and AIDS make tremendous new demands on health services that cannot be met by hospitals alone. Because HIV infection and all its accompanying complications can last for months or years, a person with HIV infection or AIDS may move from the home to the hospital and back again several times. Hospital care is very expensive, and families can often not afford multiple admissions to hospital. Hospitals themselves do not have the personnel and resources to cope with the huge demands that AIDS makes of them.

The only practical and humane solutions are to care for patients in their own homes and communities for as long as possible: to develop an integrated home based care service with professional, community and volunteer caregivers; and to use hospitals as a last

resort when patient's condition has deteriorated and professional help is needed. But the demands on families and community do not end with death of the patient. The AIDS epidemic has left behind millions of orphans and other children made vulnerable by HIV/AIDS in Africa and conditions in which these children live are often appalling. If communities do not reach out to help these children, AIDS will also kill our future generation (Van Dyk, 2008:33)

2.8 Rationale for Home Based Care Givers

Due to AIDS epidemic's impending additional impact on communities, in South Africa as a whole, it is necessary to consider how best to provide care for people with diseases and their families. As more people become ill with AIDS-related diseases and other chronic conditions, many are not able to stay in hospitals or hospices. For many, the home is a more appropriate place for care.

It is also recognized that South Africa has limited health care resources. Situations will arise where hospital or other institutional care may not be possible.

The reasons for this include:

- Shortage of hospital beds
- Insufficient medical and nursing staff
- Not enough money for health care
- Increasing demands by other patients who have acute (curable) conditions, which need to be managed in hospital (Department of Health, 2004: 6)

HBC can also provide support when patients, who should be in hospital, are not admitted or are discharged too early. It is not intended to be 'second class care' for those who cannot afford to be in hospital; there may be benefits in caring for the patient at home. Ill people may choose to go home if they feel comforted in their own surroundings with familiar people around them (Department of Health, 2004:6)

2.9 Principles of Home Based-Care



- Holistic: physical, social emotional, economic and spiritual. Community needs are addressed, and integrated into existing systems
- Person-Centered: sensitive to culture, religion and value systems hence respect privacy and dignity (community-driven, customer-centered).
- Comprehensive, interdepartmental and all-encompassing, preventative, promotive, therapeutic, rehabilitative and palliative (multi-sectoral involvement).
- Empowering and allows capacity building to promote the autonomy and functional independence of the individual and the family or caregivers. Leadership is from within the community.
- Ensure access to comprehensive support services.
- Cover total lifespan
- Sustainable and cost-effective resource responsibilities to be identified and shared.
- Adhere to a basic principle in health care and development, namely community involvement (Department of Health, 2004: 5).

2.10 The goals and objectives of home- based care programmes.

The main goal of home-base care programmes is to provide the organizational structure, resources and framework that will enable the family to look after its own sick members. Important functions of home based care programmes are:

- To empower the community and family to cope effectively with the physical, psychosocial and spiritual needs of those living with HIV infection and AIDS;
- To educate the community about the prevention of HIV transmission;
- To support family members in their care giving roles and
- To reduce the social and personal impact that living with HIV infection and AIDS makes on all those concerned.

A very important function of home-based care programmes is to establish a well functioning referral system to hospital, hospices, clinics and other health care facilities in the community (Van Dyk, 2008:33).

2.11 Members of the HBC team

HBC is such an enormous challenge, that no single organisation or profession can deal with it alone. A variety of resources, funds, effort and energy will be needed from the public (Government) and private sectors, and from community organisations. Collaboration is keys to HBC. For this reason, many people who are ill with different diseases will be cared at home by relatives and community members. Nurses and caregivers are also very important in helping the family and the community to take good care of the patient. (Department of Health, 2004: 6).

The HBC team may consist of family and volunteer community members and a multi-disciplinary team of social workers, doctors, psychologists, nurses, occupational therapists, physiotherapists, educators, caregivers, religious leaders and legal advisors. The team may vary, depending on the resources of each community and the patients' needs. The majority of the team may be volunteers, often from churches and social groups such as youth organisations. When properly trained and well supported, volunteers can play a major role in closing the gap between professional services and patients (Department of Health, 2004: 7).

In the past, many organisations in sub-Saharan Africa have experienced difficulty with HBC programmes, especially in sustaining the motivation and activities on an ongoing basis. Programmes are often dependent on the participation of volunteers for little or no remuneration. The lack of resources is often the biggest challenge. Creative ways need to be found to overcome these problems (Department of Health, 2004: 7).

HBC focuses on all levels of care and not only for people who are ill with AIDS-related diseases. Even a person who is newly diagnosed with HIV can benefit from some form of HBC. Whether HBC is for a person who is healthy or ill, caring for people at home requires more than just taking care of their basic medical needs. It means looking after the person and helping them do what they would usually do for themselves (for example, bathing and eating). HBC should attempt to deal with all aspects of a person: physical, social, emotional and spiritual needs. It aims to help an ill person in such a way that dignity is maintained. The patient should be encouraged to do as much as he can for himself. By involving the community, the HBC team can provide a wide range of services to patients and their families (Department of Health, 2004: 8).

2.13 Types of activities of Home Based Care

The Collins English Dictionary (1991:244) defines ‘care’ as “to provide physical needs, help or comfort (for); to look after someone and keep them in a good state or condition”. Home care involves the provision of health services by both formal and informal caregivers in the home, in order to promote, restore and maintain a person’s maximum level of comfort, function and health including care towards a dignified death according to the Department of Health’s guidelines on home-based and community based care. Home and long-term care has become necessary due to the advent of HIV/AIDS as well as the increase in chronic illnesses. This is compounded by the spiraling costs of institutional care and the lack of adequate hospital beds. Thus home care is provided to replace acute care to prevent the need for institutionalization and maintain individuals in their own homes and communities, which are familiar to them so that they can enjoy quality of life (WHO 1999:11).

The Department of Health’s (DOH 2001:1) guidelines indicate that home care is comprehensive and includes provision of basic physical, emotional, psychological and spiritual support as well as a preventive, promotive, therapeutic, rehabilitative and

palliative care services in the home environment. In the United States of America (USA), home care has evolved to become a prominent sector in the health care system where managed care is provided by agencies (Rappaport 2000:15).

The findings and recommendations of the 1st Southern African Regional Community Home-based Care Conference (HDN 2001:5) defines HCBC as care given to individuals in their own natural environment by their families supported by skilled personnel and communities. Regarding the plight of AIDS patients in rural South Africa, Hardman (2001:13) found that volunteers visit ill patients in their homes and provide holistic care. In Uganda, terminally ill patients are cared for in their homes (Hardman 2001:13).

In a study in Kenya to determine the priority needs and interventions necessary to plan, develop and implement community home –based care and the impact of caring on women and children the World Health Organization found that caregivers are mostly uneducated and need psychological support and Counselling. Furthermore, care to family members and siblings were provided by children, mostly girls but at times also boys.

It was noted that elderly people mostly grandmothers had taken over the care giving role in the absence of or after the death of adult children. Some caregivers did not know the cause of the illness of their clients and had little understanding of diseases. Caregivers mostly work on a volunteering basis and are often linked to NPOs and church groups. Many lack resources and supplies to provide the service and live in poverty themselves. Time spent providing care ranges from two to ten hours daily (WHO 2001:31-37).

Although men are generally traditionally excluded from providing HCBC, a group in Kenya, Movement of Men against AIDS in Kenya (MMAAK) Provide care to HIV-positive men, which include group therapy and Counselling (Home-based care: 2004:23)

In Zimbabwe where men are not generally involved in soft care as this is traditionally not their role, they increasingly support HIV-positive men and use their influence to advocate for sustainable HCBC (Dongozi, 2005:11). In a study on models of community/home-

based care for people living with HIV/AIDS in southern Africa, Ncama (2005:35) found that roles of caregivers vary depending on the service model of home-care offered. Caregivers providing home visits, mainly visit patients and spend time talking to and educating them and their family. They also provide household support, such as cleaning and cooking, and accompany them to health facilities.

In the African context, family member as caregiver has traditionally been the accepted practice especially in the rural setting. Similar practices are found in the UK and USA, although these primary carers are supported to some degree by professional staff, which is not generally the case in Africa (Rice 2001:24)

The role of caregivers includes the provision of basic health care, such as changing dressing; physical care including bathing, dressing, changing soiled linen, cooking, and symptom management, fetching wood and water, and cleaning the home (WHO 2001:34). Home based care givers are also involved in:

- Supporting family members caring for patient or orphans.
- Material assistance (for example, food, clothing, money through the church).
- Building material and labour.
- Basic medical care.
- Basic nursing care.

2.14 Advantages of Home Based Care Givers

- Home based care is often the best way to look after someone with AIDS. Some of the reasons why home-based care is preferable to hospital care are the following:
- Good basic care can be successfully provided in the home.
- People who are very sick or dying often prefer to stay at home so that they can spend their last days in familiar surroundings-especially when they know they cannot be cured in a hospital.

- 2.1
- Sick people are comforted by being in their own homes and communities with family and friends around them. The ambience of home prevents the patient from feeling isolated and rejected.
 - Home-based care allows the patient and family time to come to grips with the illness, and to prepare for the impending death of the patient.
 - Home-based care promotes a holistic approach to care. This means that the physical, social, cultural, psychological, emotional, religious and spiritual needs of a patient can all be fulfilled by the family and the health team.
 - Home-based care can be comprehensive if it includes rehabilitative, preventive, promotive, curative and palliative care.
 - It is usually less expensive for families to care for someone at home. The cost of hospitalization and transportation to and from a hospital can be financially crippling.
 - If the sick person is at home, family members can attend to their other responsibilities more easily. It can become very difficult to cope with one's own life if a loved one is in hospital and the caregiver has to make frequent trips to and from the hospital.
 - Because the pressure on hospital is reduced by home care, doctors, nurses and other health care professionals can attend to other critically ill patients in hospitals.

Home-based caregivers are also in the ideal position to identify the needs of children who are affected by the illness of parents or siblings. They can assess issues such as whether the child is involved in the care of patient, and to what extent; whether the child is immunized; whether the child needs health care; and whether the child has time to play. The home-based caregiver is also in a position to know who supports the child psychologically and emotionally; whether the child understands what is going on in the family; and who will look after the child after the death of the parent (Van Dyk, 2008:324).

2.15 Potential problems associated with home-base care

The following are potential problems associated with the home-based care:

- Patients often feel isolated-especially when they are confined to the home or to the bed.
- Many people in communities are not ready for home-based care because of ignorance, superstition and the fear of being stigmatized by other members of the community. For these reasons people might reject the concept of home-based care. This increases the anguish, desperation and loneliness of those living with AIDS.
- Non-compliance with treatment often occurs because the patient or primary caregivers do not know how or when to administer medication (because they are educationally disadvantaged) or the medication they require is far too expensive and they do not know where to go for financial aid.
- A lack of knowledge about the disease, treatment, emergency situations and community resources often hampers home based care, and many family caregivers are afraid that they themselves might become infected with HIV.

One of the greatest drawbacks of home based care is that the caregiver might give up because of exhaustion and burnout resulting from the extreme demands of caring for a terminally ill patient. It is absolutely vital for caregivers to have support systems and to know how to care for themselves; otherwise they will be overwhelmed by burnout (Van Dyk, 2008:324).

2.16 Models of Home- based care

The following are different models of home based care:

2.16.1 The integrated home-based care model

This model links all the service providers with patients and their families in a continuum of care. The patient and family are supported by a network of services, such as community caregivers, clinics, hospitals, support groups, non-governmental organizations (NGOs) and community-based organizations (CBOs), as well as by the larger community. This integrated model allows for referral between all partners as trust is built and it ensures that community caregivers are trained, supported and supervised (Van Dyk, 2008:324)

The integrated home-based care model is ideal for quality physical care and psychosocial support for the person living with HIV/AIDS (PLWHA) and his or her family (Van Dyk, 2008:325).

2.16.2 Single-service home-based care model

In this model, one service provider (usually a clinic, hospital, NGO or church) organizes home-based care by recruiting and training volunteers then brings them into contact with patients and their families at home. Many home-based care programmes start this way and build their way up to offer integrated care as they recruit other partners (Van Dyk, 2008:324).

2.16.3 Informal home-based care setting model

It is in this model that families care for their sick loved ones at home, with the informal assistance of their own social network. Nobody has any specific training or external support and there is no formal organization or supervision of the care. Informal care can be very difficult because the primary caregivers often lack the necessary knowledge, skills and emotional support needed to care for AIDS patient (Van Dyk, 2008:324).

2.17 The Role of volunteers in home-based care

Local community volunteers play a very important role in home-based care programmes. Volunteers usually come from a variety of background and they may be trained and experienced professionals, trained community caregivers, family members, or compassionate community members who wish to help those in need.

Many of the perceived disadvantages of using volunteers can be overcome if the volunteers are recognized as key worker in the Programme, if they are chosen by members of the community, and if they are properly trained in basic home care.

Volunteers should never be expected to offer home-based care without a good basic training and understanding of the physical, psychosocial, emotional and spiritual conditions that they may encounter and how to deal with these (Van Dyk, 2008:324)

Volunteer programme managers should note the problems and frustrations of volunteer workers and address problems appropriately. The health system cannot afford to have valuable volunteer workers resign out of frustration. The following problems were reported by volunteers working in the HIV/AIDS field.

- They work in isolation;
- They do not have a voice in decisions that affect them and their work;
- The finances available for volunteer workers and important prevention projects are often cut drastically;
- Creativity is discouraged because innovative ideas and suggestions are not implemented; they have too little autonomy and responsibility;
- Volunteer caregivers often struggle with over involvement and a lack of boundaries between them and their clients. This results in stress, burnout and resignation (Van Dyk, 2008:324).
- The burden of caring for people living with HIV and AIDS, as either primary care givers or volunteers, is disproportionately provided by women. Men rarely assist with care giving (Akitola, 2004:34).

2.18 Training of home-based caregivers

It is important to train home-based caregivers properly and thoroughly to provide a high standard of holistic care. The training provided will depend on the level of care required, but the following should be included in any training programme:

- Background to home-based care;
- Communication skills, including communication with children;
- Basic counseling skills;
- Promotion of positive living;
- Spiritual and religious issues;
- Bereavement counseling;
- Gender and cultural issues;
- Infection control in the home-based care situation;
- Basic nursing care principles and the management of common illness;
- Practical procedures to help the patient, for example, wound dressing, mouth care, feeding, bathing in bed, shaving, and using a bed pan;
- Nutrition and problems influencing nutrition. Social support, community support and referral possibilities and
- Care of the caregiver to cope with a very demanding task (Van Dyk, 2008:324)

2.19 Conclusion

This chapter discusses the literature review conducted for the study. Some of the aspects covered in this chapter are: magnitude of HIV and AIDS, rationale for home-based care principles of home based-care, aims and objectives of home based care, members of home-based care team, scope of home-based care, frame work for home-based care and legal , ethical and policy issues. There is ample research that indicates that caregivers experience many challenges, particularly stress and burnout. Their reactions include emotional exhaustion, despair, depression and helplessness. Many studies on stress and burnout of caregivers have focused more on the negative and difficult aspects of work

done by HBCGs, and reward of care and motivating factors that keep HBCGs doing this work are not fully considered.

It is clear that most studies on coping regard stress and burnout as major challenges that influence the choice of strategies the HBCGs opt for to deal with the challenges they encounter during the course of their work. Mostly studies focus on coping strategies of health workers in hospitals, or of HIV/AIDS patients, but seldom on HBCGs in a HBCC, especially in townships. In light of the above, this study will focus specifically on Hamphaphuli Tribal Authority. The next chapter will cover the research methodology employed in this study.

3.2 Area of study

This study was conducted in the Mphahlele area, in the Thabazimbi Municipality which is part of Vhembe district, Limpopo province in South Africa. The Mphahlele area is mainly rural in nature. It also has a high statistic of people living with HIV and AIDS. The specific areas for the study were three villages, namely, Mphahlele. In these three villages, there are two home based-care centers.

These villages are approximately five kilometers apart from each other and approximately fifteen kilometers from Thabazimbi town. In these villages, vegetation is dominated by fruit trees and indigenous plants. The population consists of a high percentage of young people and the aged. The level of unemployment is high in these villages. In most cases the source of income is from government grants, namely, old age grant, foster care grant and child support grant.

3.3 Research Design

In the present study, the research design discussed was based on Leedy and Ormrod (2001:91-92). According to these writers, in planning the research design, it is extremely important for the researcher not only to choose a viable research problem but also to

3.1 Introduction

In the previous chapter, a study of literature was done. This chapter will focus on the research methodology followed in conducting the research. Research methodology is described the way the study is going to be carried out. This chapter will focus on the following elements of research methodology.

3.2. Area of study

This study was conducted in Ha-Mphaphuli area, in the Thulamela Municipality which is part of Vhembe district, Limpopo province in South Africa. Ha-Mphego area is mainly rural in nature. It also has a high statistics of people living with HIV and AIDS. The specific areas for the study were three villages, namely, Ha- Mphego. In these three villages, there are two home based-care centers.

These villages are approximately five kilometers apart from each other and approximately fifteen kilometers from Thohoyandou town. In these villages, vegetation is dominated by fruit trees and indigenous plants. The population consists of a high percentage of young people and the aged. The level of unemployment is high in these villages. In most cases the source of income is from government grants, namely, old age grant, foster care grant and child support grant.

3.3 Research Design

In the present study, the research design discussed was based on Leedy and Ormrod (2001:91-92). According to these writers, in planning the research design, it is extremely important for the researcher not only to choose a viable research problem but also to

consider the kinds of data an investigation of the problem will require and feasible means of collecting and interpreting those data

Qualitative research design is the standard experimental method of most disciplines. Quantitative experiments use a standard format, with a few minor interdisciplinary differences, of generating a hypothesis to be proved or disproved. In quantitative research a researcher knows clearly in advance what is looking for. Researcher uses tools such as questionnaires to collect numerical data. Data is in the form of numbers and statistics.

The researcher used exploratory research design as he wants to explore the challenges faced by home-based care givers in dealing with HIV and AIDS. The researcher explored the socio-economic and physical challenges, psychological challenges, psychological needs and the coping strategies regarding the problem and the kind of social support services required by the study group.

3.3 Research Methodology

Research methodologies refer to the rationale and the philosophical assumptions that underlie a particular study (Leedy, 2004:898). According to Huysamen (1995:163) research methodology is the creation and development of techniques and strategies to collect data, the development of methods to investigate and improve the psychometric properties such as reliability and validity of the data obtained by means of these techniques and the analysis of such data. In this study, research methodology involves a selection of appropriate research approaches, research methods, sampling procedures, respondents and instruments for collecting and analyzing data.

3.3.1 Quantitative research method

In this study the researcher used quantitative and qualitative methods, although, quantitative methodology was dominant. The use of different methodologies according to Babbie (2007:113) to test the same findings is called triangulation.

According to Leedy (2004), quantitative approach is based on positivism, in which scientific explanation is adopted. Quantitative data collection methods are based on measurements using verification instruments in order to objectify phenomena under study. Measuring instruments involves the assignment of numbers, in terms of fixed rules, to reflect differences between them in some of their characteristics.

3.3.2 Qualitative research method

According to Struwig and Stead (2001:12), qualitative researchers are interested in understanding the issues being researched from the perspective of the research participants. In other words they are trying to see through the eyes of the participants. Struwig and Stead (2001:17) further enforce the above statement by stating that the researcher and the participant are both involved in the research process in qualitative research with the researcher trying to understand and interpret the participant's perspective. McMillan and Schumacher (1993:14) strengthen the above statement by stating that qualitative research is more concerned with understanding the social phenomenon from the participant's perspectives.

In this study a qualitative approach was used as it provided the researcher the opportunity to determine and experience firsthand the challenges, perceptions and experiences of the research participants in their natural settings. The researcher interacted with the research participants by observing them at their schools. Burns (2000:11) states that qualitative forms of investigation tend to be based on recognition of the importance of the subjective, experiential life world of human beings.

The researcher will attempt to report the findings as truthfully and as unbiased as possible taking into account not to lose the value and importance of the information gathered from the participants. Burns (2000:388) states that: The qualitative researcher is not concerned with objective truth, but rather with the truth as the informant perceives it. The qualitative

researcher thus tries to understand the meanings individuals give to the world in which they live.

3.4 Population of the Study

According to Bless and Smith (2005:194), population is referred to as the set of elements that the research focuses upon and to which the obtained results should be generalized. It is also defined as the total set from which the individual or units of the study are chosen. Population is also seen as the set of elements that the research focuses upon and to which the obtained results should be generalized (Seaberg, 1988:240).

Non-probability, purposeful sampling was used to ensure that the respondents were selected based on their knowledge of the phenomenon. Purposeful sampling is done when researchers select a sample based on existing knowledge of the population and the purpose of the research. This is a method of choice. The advantage of this form of sampling is that it is possible to acquire rich data from informed participants (Streubert & Carpenter 1999:58). All home based carers found in Ward 24 of the Thulamela Municipality will compose the population of this study.

3.5 Sampling

Mouton further mentions that the aim of sampling is to produce representative selection of population elements. With regards to presentation Wimmer and Dominick (1983:58) mentioned that a sample that is not representative of population, regardless of its size, is inadequate for testing purposes. The results cannot be generalised for the population.

Cohen and Manion (1989:10) view a sample as a smaller group or subset of the population from which the researcher attempts to collect information so that the knowledge gained typifies the total population under study. Best and Kahn (1993:13) also share similar views regarding sampling by defining a sample as a small proportion of a population selected for observation and analysis.

In conclusion, sampling makes it possible to estimate characteristics of a large group by examining the characteristics of smaller groups. The larger group is referred to as a population. The smaller group drawn from the population is called sample.

3.6 Sampling Method

Sampling can be defined as a subset or portion of the total population. The sample must always be viewed as an approximation of the whole rather than as a whole in itself (Bailey, 1994:84). According to Devos (2005:194), a sample is that which comprises elements of the population considered for actual inclusion in the study, or it can be viewed as a subset of measurements drawn from a population in which one is interested.

Non-probability, purposeful sampling will be used to ensure that the respondents are selected based on their knowledge of the phenomenon. Purposeful sampling is done when researchers select the sample based on existing knowledge of the population and the purpose of the research (Babbie & Mouton 2002:166).

In purposive sampling, the researcher does not necessarily have a quota to fill from within various strata, as in quota sampling, but neither does he or she just pick the nearest warm bodies, as in convenience sampling. Rather, the researcher uses his or her own judgment about which respondent to choose, and picks only those who best meet the purposes of the study (Bailey, 1994:96).

The researcher visited the two home based care centers in order to access the list of home based care givers from the two center managers: Home based care givers who have less than three years as home based care givers were excluded in the study as their responses would have not been relevant to the study.



According to Wimmer and Domminick (1988:68), determining an adequate sample size is one of the most controversial aspects of sampling. How large a sample should be in order to be representative of the population has no simple answer (1983:68)? Best and Kahn (1993:19) stated that there is no fixed number or percentage of subjects that determine the size of an adequate sample. It may depend upon the nature and the population of interest or data gathered and analysed. 120 respondents were interviewed, 50 Home Base Care Givers, 10 Professional nurses, 10 traditional leader, 10 HIV Patients and 30 Stakeholders.

3.8 Data collection methods

As noted by Mouton (2002:156), data collection subsists in the use of a variety of methods and techniques of data collection in a single study. Schulze (2002b: 14) maintains that data should meet the requirements of a qualitative or quantitative research design or a design consisting of a combination of these approaches. The data collection methods in this study combined these two approaches. In an effort to acquire different facets of the same problem (symbolic reality) of the participants (Berg 1995: 4) and obtain more valid results in the research, the following method was used to collect data: questionnaires.

3.8.1. Questionnaires Survey

For many good reasons, the questionnaire is the most widely used technique for obtaining information from subjects (McMillan and Schumacher 2001: 257). Furthermore, McMillan and Schumacher (2001: 257) note that a questionnaire is relatively economical, has the same questions for all subjects and can ensure anonymity.

A self-administered and self-contained structured questionnaire was designed by the researcher and was used to collect relevant standardised data from all subjects in the

sample. McNamara (1997:105) describes the structured or close ended item as the mainstay of survey researches. The questionnaire technique was chosen because it had several advantages. Close ended items are amenable to statistical data analysis with minimal manipulation of raw data. MacNamara (1997:105), states that questionnaires can access a large sample which place minimal demands on personnel, and can be totally anonymous. The reasons for using questionnaires in this study was that as a data gathering instrument it was cost effective, easy to complete and timeliness of responses.

The instrument's items, format and procedures was taken from Noveno (2003:13); however, some modifications were made by the researcher to fit to the current study. The questionnaire consisted 10 items. The first part of the instrument contained a statement of purpose and directions, and was designed to collect biographical or personal data that include gender, age, and civil status, educational attainment and years of work experience.

The second part of the questionnaire consisted directions and 20 five point Likert-scale items for rating personnel's perceptions of challenges and managing mechanisms of Home-Based caregivers for patients living with HIV/AIDS in Vhembe District, Limpopo Province. The items asked participants to rate the extent to which they agreed or disagreed with certain aspects of their stay at the School. The rating scale had the following designations: 5=strongly agree; 4=agree; 3=Uncertain; 2=disagree; 1=strongly disagree. The Likert type scale was employed because it provided greater flexibility since the scale descriptions varied to fit into the nature of the question (McMillan and Schumacher, 1993:245).

During the interview the likert questions will be used and they will cover the following variables:

- The socio economic and physical challenges faced by home based carers.
- The psychological needs of the study group.
- The kind of support services required and available to the study group.

- The coping strategies of home based carers.

3.8.2 Interview

Graven et al (1995:21) define the interview as an organized way of asking questions. The questions formulated within the interview need to be relevant to the problem under investigation. Interviews involve *verbal interaction* between individuals and serve as a specialized form of communication between people for a specific purpose associated with some agreed subject matter (Anderson, 1990:222). Bogdan and Biklen (1992: 96) and Cohen and Manion (1980:241) view the research interview as a two-person conversation initiated by the interviewer for the specific purpose of obtaining research relevant information, and focus by him on content specified research objectives of a systematic description, prediction or explanation. Researchers send interviewers to ask the questions orally and record a respondent's answers. Interviews were implemented in this research to serve the purpose of collecting data from different respondents such as Health caregivers, Officers of the Department of Health.

3.9 Data analysis

Mouton (1996:161) points out that the term 'analysis' basically means the resolution of a complex whole into the parts. It involves reducing to manageable proportions the wealth of data that one has collected or has available. According to Fraenkel and Wallen (1990:47), data analysis is the process of simplifying data in order to make it comprehensible. Earlandson, Harris, Skipper and Allen (1993:111) define data analysis as the process of bringing order, structure and meaning to a mass of collected data. In this study data analysis is the process of systematically searching and arranging the interview transcription, field notes and other materials that are accumulated to increase the researcher's own understanding of them and to enable one to present what one has discovered.

Statistical Package for Social Sciences (SPSS) is a software system developed in 1968 by Norman H. Nie, C. Hadlai (Tex) Hull and Dale H. Bent. They developed it based on the idea of using statistics to turn raw data into information essential to decision-making. They also developed it out of the need to quickly analyze volumes of social science data gathered through various methods of research. These three innovators were pioneers in their field, visionaries who recognized early that data and how you analyze it is the driving force behind sound decision-making.

3.10 Ethical considerations

Researchers need to be aware of ethical issues before entering the field (Neuman 2000), especially when dealing with sensitive topics such as those that are HIV/AIDS-related and touch on the emotional and psychological aspects of all human spheres in society. The following ethical issues were considered in this study:

3.10.1 Consent and voluntary participation

The researcher obtained consent from each one of the participants who participated in the study. According to Terre Blanche and Durrheim (1999:66), participants need to receive a full non-technical and clear explanation of what is expected of them so that they can make informed choices to participate voluntarily, or not. An information session was arranged by the centre administrator for the researcher to meet potential participants, where she explained what was expected of them, including all the steps to be followed during the research, and informed them of their right to discontinue their participation at any time despite giving initial consent.

They were therefore granted the opportunity to accept or decline their participation in the study, rendering consent on a voluntary and informed basis. Consent forms were given to all the volunteering participants to fill in and return during interviews. All the participants who were interviewed handed their signed consent forms to the researcher prior to the commencement of the interview.

The participants were also informed that the researcher would always be available if they should need further clarity. Prior to observation, the participants were requested by the researcher to seek consent from the PALHIV to bring her along during visits. According to Babbie and Mouton (2001:520), participants must be informed that they should not expect any special rewards in participating in the study. Clarity on that was also provided during the information session, to avoid creating any possible expectations of being rewarded.

3.10.2 No harm to participants

According to Babbie and Mouton (2001:522), social research should never harm or injure people participating in a study. The researcher ensured that the participants were not exposed to any danger. Interviews were held at the centre, an environment they are familiar with and which is also safe. During observations the researcher drove the participants in his car to visit patients, thereby minimising any potential danger they might have been exposed to.

3.10.3 Confidentiality

According to Terre Blanche and Durrheim (1999:68), in the consent form that the participants sign, they must be assured of the parameters of confidentiality of the information they will supply and that will be shared with them during the information session. Part of the information shared with participants during the information session included the confidentiality parameters relevant for this study, which were also included in the consent (in English and Tshivenda). In this study no names and addresses are used, HBCGs participating in this study are addressed only as research participants, and pseudonyms are used when referring to them.

3.11 Conclusion

In this chapter the research methodology has been discussed for this study. The researcher concluded that the population and sampling procedures as well as research instruments, data collection techniques and data analysis were more appropriate in the methodology. Population and sampling procedures indicated all respondents involved in the research and how they were selected to form a sample. Interviews were used as data collection instrument to guarantee the success of this research. In Chapter four, the research focuses on research findings, analysis and interpretation.

CHAPTER 4: DATA PRESENTATION, INTERPRETATION AND ANALYSIS

4.1 Introduction

The analysis of research data and the findings of this study will be presented in this chapter. Data were obtained from individual in-depth interviews with fifteen (15) clients who are living with HIV and AIDS in the Ha-Mphaphuli area of Limpopo province. The chapter begins with the description of the analytic process which includes data coding, organization and reduction as described by Greenlagh (2007:79); Polit and Beck (2004:573) as data management. The authors assert that identification of themes or concepts and sorting them is crucial at this level.

The researcher utilized data collection techniques carefully in order to promote quality of the process of obtaining data from participants which has produced credible results. The researcher used a guide to interview participants. It is worth stating that some questions on the guide had to be probed further in order to arrive at the theme of the study. Participants were free to respond in the language that they were familiar with. Almost all participants responded in Tshivenda which is the common language in the study area.

The study was conducted in the months of June and July, 2012. Two nurses who were currently working in the field of community home based care assisted in the study. Interviews took place in the homes of participants and at certain points; pictures were taken after seeking consent from the owners. Considering that issues of HIV and AIDS are still sensitive in the study area, a one to one discussion was done in a private room where nobody else could listen to the discussions. At the end of the interviews, participants were given chance to ask questions or to give any comments they had concerning the theme of the discussions.

4.2 Demographic Characteristics of participants

This section consisted of five areas. Although these areas were not directly concerned with the purpose of the study, demographic information was collected and analyzed to determine the characteristics of the participants under study. The data comprised the age, sex, employment status, level of education, and marital status of the participants. (120) participants took part in the study. Data yielded the following results:

Table 4.1: Gender Distribution of the respondents

	Frequency	Percentage
Male	48	40
Female	72	60
Total	120	100

Out of the 15 participants interviewed, 60% (n =72) were females while 40% (n = 48) were males. The males interviewed were aged between 26 and 45 years. This shows that the majority of the participants were women. Table 4.1 presents the percentage of males and females interviewed.

The AIDS pandemic has presented women with a massive dilemma in their sexual relationship with men, making prevention of HIV transmission through safer sexual practices problematic for them. The Centre for Disease Surveillance and Reporting (2000) has reported that over 95% of all cases and 95% of AIDS deaths occur in the developing world mostly among young adults 20-45 years and increasingly among women.

The incidence of HIV infection in women is growing at a proportionately faster rate than in any other population group with heterosexual transmission being the most significant source of infection. Gender based factors have been associated with an increased risk for HIV in women from many perspectives including sexual power imbalance, economic

issues and traditional socialization of men and women. Biological, social and cultural factors commonly referred to as gender-based factors place women at an increased risk to HIV infection hence receiving Community Home Based Care services in the homes.

Table 4.2: Occupational status

	Frequency	Percentage
House Wife	48	40
Small scale business	24	20
Employed	24	20
Pensioner	8	7
School dropout	16	13
Total	120	100

Table 4.2 explains participants' employment status. Five categories of employment status were included. The majority of the participants 40% were housewives with no other type of work. 24 participants stated that they do some business on a small scale. Of the three participants, two were males and one was a female. Another 20% of participants had permanent jobs and these were all males. 24 participants were employed, 20 were watchmen and the 16 participant was a primary school teacher. 8 participant was a pensioner and 16 were school dropouts (see table 4.2).

HIV infection is mostly confined to the poorest, who constitute the most of those infected in Vhembe district. This is not simply that information, education and counseling activities are unlikely to reach the poor but that such messages are often irrelevant and inoperable given the reality of their lives. Poverty is a crucial factor in the spread of HIV and AIDS. Similarly, poverty plays a central role in perpetuating teenage marriages. Although results are like this, CHBC services are common to all occupations.

Table 4.3: Level of education

	Frequency	Percentage
Never attended school	24	20
Primary school	60	50
Secondary school	32	27
Tertiary school	4	3
Total	120	100

Table 4.3 display a total of 50% respondents (n=60) who went through primary school education. Of the eight participants who had primary school education, 20 were males and another 40 were females. Four participants (27%) had secondary school education. 3% of the respondents went as far as college or university level. However, 20% of the participants (n =24), stated that they never attended any type of school and all these were females. It is also important to note that literacy rate in Vhembe district is very low with only 39% of the adult population able to read and write. Once in school, males tend to progress further in their schooling than females.

Secondary school enrolment is only eight percent for males and three percent for females in rural areas. In Vhembe district, education for all has not yet been achieved though the importance of education especially for females has been emphasized in the country. Despite free primary school education which was introduced in 1994, limited access to education, poor quality of education, high rates of drop out and failures especially for females are still the underlying constraints

4.3. Quantitative data analysis

The obtained information from questionnaires was first coded for each and every question and then entered in the Microsoft excel spreadsheet in words and number. Data from questionnaires was analysed by means of using tables and figures. The entered data from the spreadsheet was exported to the SPSS so that it could be analysed to yield the results.

Table 4.4: Marital status

	Frequency	Percentage
Married	48	40
Single	16	13
Divorced	16	13
Widow	32	27
widower	8	7
Total	120	100

Findings indicate that the majority of the participants, 40% (n=48) were married and still living together at the time when interviews were conducted. Two participants (13%) were single and another 13% of the participants (n=16) were divorced and these were both females. Four participants (27%) were widows and one participant (7%) was a widower. As shown in Table 4.4 the marital status of the participants appears.

The fact that the majority of the participants (40%) are married, chances are high that HIV and AIDS can easily spread. It is therefore important that married couples should be expected to embrace fidelity which might decrease the spread of HIV and AIDS among themselves. An observation made from the findings of this study is that, the majority of the participants who were married were men. Another observation important to be made is that, all the participants who were divorced were females. This brings the assumption that when women are found HIV positive, they are divorced. At the same time one may conclude that men who are found HIV positive receive full support from their spouses.

4.3 Quantitative data analysis

The obtained information from questionnaires was first coded for each and every question and then entered in the Microsoft excel spreadsheet in words and number. Data from questionnaires was analysed by means of using tables and figures. The entered data from the spreadsheet was exported to the SPSS so that it could be analysed to yield the results.

Table 4.5: There is a stigma attached to the HIV/AIDS sufferer

	Frequency	Percentage
Strongly Disagree	24	20
Disagree	12	10
Neutral	6	5
Agree	48	40
Strongly Agree	30	25
Total	120	100

HIV/AIDS is affecting many countries and Southern Africa in particular. The presence of HIV/Aids was accompanied by stigma directed to sufferer of the disease. This is well supported by table 4.5, where 78 respondents representing 65% of the total sample agreed that there was a stigma attached to the HIV/Aids sufferers. This could be based on the fact that people associate the spread of HIV/Aids with sexual relationship only.

The fact that 36 respondents representing 30% of the total sample disagreed that there was a stigma attached to the HIV/Aids sufferers could be based on the fact that some people knew many ways in which HIV/Aids could be transmitted from one individual to another, and due to ignorance it is not surprising to have respondents behaving like that.

Table 4.6: The health care gives helping patient

	frequency	Percentage
Strongly Disagree	18	15
Disagree	12	10
Neutral	6	5
Agree	36	30
Strongly Agree	48	40
Total	120	100

In view of Table 4.6, 84 respondents constituting 70% of the total sample agreed that the health care givers were indeed helping patient's .Those 30 respondents constituting 25% of the total sample who disagreed knew very little about the mammoth task the health care givers were doing to patients .It must noted however that hospitals used to refer patients home particularly for home based care activity and due to misconception 6 respondents constituting 5% of the total sample were neutral.

Table 4.7: Home based care givers are well funded

	frequency	Percentage
Strongly Disagree	24	20
Disagree	52	43
Neutral	8	7
Agree	24	20
Strongly Agree	12	10
Total	120	100

Home based care givers depend upon Ngo for funding and funding takes a very long process due to documentation processes. Unless the business plan were well organized. The process of funding materialized. This is well supported by Table 4.7 in which 76 respondents constituting 63% of the total sample disagreed that home based care givers were well funded. They do not have specific time to get money as payment is depended upon the generosity of the NGO for funding. If funding from NGO were not secured payment is not affected. Funding from Ngo has it's up and down and this is likely to affect home based care givers and a very negative way. The above Table indicates that 36 respondents constituting 30% of the to sample agreed that home based care givers were well funded, something which could solely based on misconception of the environment surrounding the home based care be . Of course 8 respondent constituting 7% of the total sample was neutral and this could be due to ignorance of the activities of the home based care givers in the area.

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Table 4.8: The Government fully supported the Home based care givers.

	Frequency	Percentage
Strongly Disagree	36	30
Disagree	42	35
Neutral	6	5
Agree	20	17
Strongly Agree	16	13
Total	120	100

This study investigated the role of the state in supporting Home based care givers and this study found out that the help had mixed feeling about the respondents who are 78 constituting 65% of the total sample disagreed that the government fully supported the Home based care givers fall under a company which has the prerogative of paying the care givers concerned. Although the state has the responsibility of paying the money it very often the care givers are given little but the government in turn dies nothing so the disagreement by respondents could be valid 36 respondent constituting 30% of total sample agree that the government statement above and this could be based on the fact that certain respondents know very little as to how money is expended from government to tender interference .It does not surprise anybody to note that 6 respondents constitute 5% of the total sample were neutral for it likely to find confused respondents amongst the community .

Table 4.9: Patient respect the role of home based care givers

	Frequency	Percentage
Strongly Disagree	12	10
Disagree	12	10
Neutral	6	5
Agree	48	40
Strongly Agree	42	35
Total	120	100

It seems the majority of respondent value the work being rendered by home based care givers. This is clearly visible in Table 4.9 who 90 responded constituting 75% of the total sample agreed that patient respect the role of the home based care givers. In view of the pretend scenario hospitals very Offer send patient home .and the Home based care givers play a critical position in assisting patients at home contrary to the above statement 24 respondent which constitute 20% of the total sample disagreed that patient respect the role of Home based care givers the nation which may probably be based on misconception as Home based care givers mostly assist patient at Home on voluntary capacity and those who disagreed were informed. We are likely to find respondents who were always neutral due to lack of information. This was revealed by 6 respondents constituting 5% of the total sample.

Table 4.10: Home based care givers access funds easily for their programmes to function.

	Frequency	Percentage
Strongly Disagree	42	35
Disagree	54	45
Neutral	6	5
Agree	6	5
Strongly Agree	18	15
Total	120	100

The Home based care givers desperately need funding but majority of respondents as stated above indicate that care givers do not access funding easily. According to Table 4.10, 96 respondents constituting 80% disagreed that donors were reluctant and it seems are always reluctant to process funding. On the contrary 18 respondents which constitute 20% of the total sample agreed that Home based care givers access fund easily. This could not surprise us as other people have serious problem of knowing the really statistics to support the idea

Table 4.11: Home based care has a future.

	Frequency	Percentage
Strongly Disagree	44	37
Disagree	46	38
Neutral	6	5
Agree	18	15
Strongly Agree	6	5
Total	120	100

The success of any project society depend on the availability of funds so the sustainability of the home based care in south Africa is society depend upon the availability of funds. This note on is supported by table 4.11 in which 90 respondents disagreed that home based care has a future .This could be based on the funding they get from donors. It seems funds are very scarce and it is not surprising to find respondents behaving like that. Against the above background that the Home based care has a future the idea which is based on the fact that the available would be sustain for some year to come. It is likely to find people who are sometimes ignorant of the dynamics of progress and changes in the organisation and in this scenario the 6 respondents constituting 5% of the Total sample were neutral

Table 4.12: Lack of financial management skills render the Home based care dysfunctional.

	Frequency	Percentage
Strongly Disagree	18	15
Disagree	12	10
Neutral	12	10
Agree	42	35
Strongly Agree	36	30
Total	120	100

Sound financial management skills are integral of based care. This notion is supported by 78 respondent constituting 65% the total sample who agreed that lack of financial management skills render the home based care organisation dysfunctional something which could be based. It must organisation are collapsing due to lack of financial management skills. Against this background 30 respondents which constitute 25% of totals sample disagreed that lack of financial management skills render the Home based care dysfunctional soothing which could be based on misconception of financial management skills in the organisation but due ignorance 12 respondents constituting 10% of respondent were neutral on the issue of financial management of home based organisation something which could be based on the lack of knowledge of the minority of respondent in the society.

Table 4.13: The management committee member has the necessary management skills.

	Frequency	Percentage
Strongly Disagree	45	38
Disagree	40	33
Neutral	11	9
Agree	12	10
Strongly Agree	12	10
Total	120	100

Since 1994 South Africa lacked the necessary skill went elsewhere for greener pastures. The lack of skill in south Africa is unquestionable something which is support by 85 respondent constituting 71% of the total sample who disagreed that the management committee member have the necessary management skill and no wonder why the home based care project do not survive the test of any time and this could be the fact the foundation is not very strong particularly in the area of management .This notion is categorically opposed by 24 respondent constituting 20% of the total sample who agree that indeed the management committee member have the necessary management skills to run the organisation.

This based less considering the lack of skill south Africa has today .The fact that these respondents agreed is based on the fact of lack of knowledge 11 respondent constituting 9% of the total sample use neutral and the dilemma could be based on lack of information on the minority of respondents could probably not know the management skills and even where they should be applied.

Table 4.14: The home based care needs training is health matters.

	Frequency	Percentage
Strongly Disagree	12	10
Disagree	6	5
Neutral	12	10
Agree	42	35
Strongly Agree	48	40
Total	120	100

Training plays integral role for the survival of any organisation the Home based care cannot be exempted. Since the world has entered the technology and information revolution there is a need for training .This is well supported by 90 respondent constituting 75% of the total sample who agreed that the Home based care needs training particular n areas of health. It must be noted however that unless intensive training is conducted the care givers can contaminate disease like HIV and AIDS disease.

There is a need for care givers to understand fully the basic principles of hygiene and general health matters contrary to the statement above 18 respondents constituting 15% of total sample disagreed that the home based givers need basis training on health matter something misconception taking note of the complexities and challenges of disease particularly the spread of HIV/AIDS in south Africa. Due to ignorance it is not surprising to note that 6 respondents who constitute 5% of the total sample are neutral who lost want to get training in this era of many disease like HIV/AIDS.

Table 4.15: There are enough gloves to handle the HIV/AIDS patient

	Frequency	Percentage
Strongly Disagree	36	30
Disagree	48	40
Neutral	0	0
Agree	24	20
Strongly Agree	12	10
Total	120	100

You cannot assist HIV/AIDS patients without glove or else you run the risk of contaminating HIV/AIDS. The Home based care givers sometimes find themselves in that situation. This is supported by table 4.15 where 84 respondents constituting 70% of total sample disagreed that there are enough glove to handle the patients something which could have been caused by lack funds from Limpopo government .contrary of the above statement on the other hand 36 respondents constituting 30% Of the total sample agreed that there are enough glove to handle the HIV/AIDS patients the fact which no one could dispute as the minority of respondents might have noticed the availability of those gloves elsewhere .The general perception is very clear based in the majority respondents who disagreed.

Table 4.16: The management of HIV/AIDS is hampered by lack of ARV.

	Frequency	Percentage
Strongly Disagree	18	15
Disagree	12	10
Neutral	0	0
Agree	48	40
Strongly Agree	42	35
Total	120	100

The Limpopo Department of health and social Development had a problem of ARV and other medicine for HIV/AIDS suffers and so this could have posed a serious problem in the management of HIV/AIDS. This notion is well supported by 90 respondents constituting 75% of the total sample who agreed that the management of HIV/AIDS was hampered by the lack of ARV. It must be noted that HIV/AIDS suffers cannot make it without ARV. Against the above background 30 respondents constituting 25% of the total sample disagreed that the management of HIV/AIDS is hampered by lack of ARV.

They support the fact that the management of HIV/AIDS is well in place. Some In this particularly survey therefore the perception existed that it was not because of the absence of ARV which led to the mismanagement but other factors should be taken into consideration apart from ARV but this notion could have its based on the lack of knowledge on the dynamics of managing HIV/AIDS towards patients of HIV/AIDS.

Table 4.17: The current management is winning the war towards HIV/AIDS.

	Frequency	Percentage
Strongly Disagree	46	38
Disagree	48	40
Neutral	2	2
Agree	12	10
Strongly Agree	12	10
Total	120	100

In view of current management of HIV/AIDS the challenges are many ranging from the availability of resources like ARV etc. Very often we hear hospital running short of medicines particularly in the Limpopo province and this has been alluded by many scholars. The survey undertaken as revealed by table 4.13 indicate that 94 respondents constituting 78% of the total sample disagreed that the current management of HIV/AIDS is not winning the war against the total eradication of HIV/AIDS. Researches are underway attempting to get the vaccine. The spread of the pandemic seems to be going amongst the youth probably because the managements of HIV/AIDS could be failing somewhere.

It must also be noted however that the home based care givers that do not operate directly with the department of Health and social Development and their morale could be down as they seem to be operating through labour brokers the constituting 20% of total sample agreed that the current management of HIV/AIDS is to winning the war against HIV/AIDS pandemic could well be based on misconception and lack of knowledge .The fact that 5 Department in Limpopo are under administration due to lack of fund could be unknown to the minority of respondents and no wonder why they support the fact that the management of HIV/AIDS is well in place. Some respondents are likely to be neutral like 2 respondents constituting 2% of total sample. This engages in research for it could be possible to find people who know nothing about the existence and management of HIV/AIDS.

Table 4.18: The home based care givers have the necessary skills to manage HIV/AIDS.

	Frequency	Percentage
Strongly Disagree	46	38
Disagree	47	39
Neutral	3	3
Agree	18	15
Strongly Agree	6	5
Total	120	100

The availability of skills is important for the proper functionality of any organisation and management of HIV/AIDS is very complex so the care givers should be well covalent with the new challenges probably due to lack of skills necessitated by lack of education and no training .At the same time the care givers do not have a clear policy which is uniform and particular to manage the HIV/AIDS. This idea is well supported by 92 respondents constituting 77% of the total sample who disagreed that the Home based care givers have the necessary skill to manage HFV/AIDS.

Training is very expensive and no private company can spend a lot of money in training so although trainings are organized for the care givers they could not be of high standard taking note of expenditure therefore .The minority of respondents in the survey who are 24 respondents who constitute 20% of the total sample .This perception survey to confirm that certain people in the community do not know what materializing on the management of HIV/AIDS and such responses are likely to occur 3 respondents constituting 3% of the total sample who are neutral could be a clear indication of a high level of confusion of certain people in community .how dare can one be ignorant while the spread of HIV/AIDS is out of proportion

Table 4.19: The management of HIV/AIDS is getting support from the media.

	Frequency	Percentage
Strongly Disagree	36	30
Disagree	48	40
Neutral	12	10
Agree	18	15
Strongly Agree	6	5
Total	120	100

South Africa like many developing nation have a powerful media but this media is not use in fullest to advance of HIV/AIDS .If this was so 84 respondents constituting 70% of the total sample would not have agreed that the management of HIV/AIDS is getting support from the media something which is being worsened by the fund attached when advertising is made why should we have to find ourselves in gambling with the lives of people .way stake holders been serious about the spread of the pandemic media would have been used in its fullest to alert the people and the management of HIV/AIDS would have improved contrary to the above 24 respondent constituting 20% of the total sample agreed that the management of HIV/AIDS is getting support from the media something one became more skeptical realizing the spread of the pandemic.

Where media is strong utilized people get the necessary information and as knowledge is power people are well capacitated. The 6 respondents constituting 5% of the total sample were neutral about the role of media in supporting the management of HIV/AIDS and something which could be based on misconception of certain people in the community.

- What are the challenges experienced by Home-Based Caregivers (HBCGs) in giving Home-Based Care (HBC) to Patients living with HIV?
- What are the kind of support provided to HBCGs in giving HBC to (Patients living with HIV) PALHIV?
- What are the coping mechanisms used by HBCGs in giving HBC to Patients living with HIV?

4.4 Qualitative data analysis

McMillan and Schumacher (2001:41) state that most interactive qualitative researchers employ several techniques in a study but usually select one as the central method. The present study has selected the qualitative technique as the central method (McMillan & Schumacher, 2001:41) further indicate that qualitative techniques provide verbal descriptions from the participant's perspective to portray the richness and complexity of events that occur in natural settings.

4.4.1 What are the challenges experienced by Home-Based Caregivers (HBCGs) in giving Home-Based Care (HBC) to Patients living with HIV?

Respondent 1 indicates that HBCGs prepare families for the eventual death of their loved ones, and advise them on steps they could take once that happens. After the death of the patient, the HBCG visits the bereaved family to give them counselling on how to deal with the death of a loved one.

Respondent 2 revealed that the roles and responsibilities of HBCGs vary from one institution to another and the availability of some HBC services depends on the

availability of funds for the programme and this is often fraught with various challenges. The HBCC in Ha-Mphaphuli had a hospice which was closed down due to financial constraints, which forced the centre to decentralise some of the services it provides, thereby changing some of the roles and responsibilities of the HBCGs.

Respondent 3 shows that most care organisations do not have resources to take on some services and that few care organisations in South Africa have taken into account the need to accommodate the changing needs and demands of their services over time, often because of lack of financial resources.

The HBCC in Ha-Mphapho Village plays an important role in the battle against HIV/AIDS, which is demonstrated by the successful running of the HBC programme. Respondent 4 indicated that the health sector has been receiving a declining portion of total government expenditure, with the sector's share having fallen from 11,5% in 2008-2009 to an estimated 10,5% in 2010/12, although it is set to increase to 10,7% by 2013. Considering the increase in the number of PALHIV, this budgeted increase may not be enough to help the sustainability of NGOs such as this HBCC in Ha-Mphaphuli.

Communities appeared to be familiar with HIV and AIDS, the burden of the disease and its consequences. Respondents cited feeling powerless and overwhelmed by HIV and AIDS. Although some basic information on HIV and AIDS was available, frequent references to low levels of access to appropriate information on HIV and AIDS were made. In addition, illiteracy was cited as a barrier to successful community education in rural areas since most educational material is produced in print form.

Respondent 4 indicated that there is poor communication in terms of disseminating the information on HIV and AIDS to this community. Most of the people are illiterate, both adult and young people. They find difficult to use pamphlets and posters. There are many posters here but it doesn't serve the purpose. The only effective way to communicate with the community is to have campaigns with the community and talk about HIV and AIDS.

4.4.2 What are the kind of support provided to HBCGs in giving HBC to (Patients living with HIV) PALHIV?

Various reasons have been given for doing this job, ranging from practical financial considerations to expressing enjoyment and love for the work, and many have stated different reasons why they continue caring for PALHIV.

Respondent 1 indicated that earning a living is one of the motivations to caregiving, as there is a high unemployment rate and few job opportunities in Ha-Mphaphuli, with an unemployment rate of 65%. This is how a research participant described earning a living to get out of poverty and hunger:

Respondent 2 revealed that compassion and a desire to help patients who do not have family members to assist them, makes caregivers wake up in the morning and go to work. She feels concern for the patients she provides services to, as respondents realises that some of them will not survive this battle without her help

Respondent 3 reveals that I feel sorry for my patients; without us they won't survive.

Respondent 4 indicated that carers acknowledged that PALHIV need their support and they believe they can make a difference in their lives, as also implied by one of the research participants.

Respondent 5 indicated that they viewed their job as meaningful and important because they were helping community members who were ailing.

Respondent 6 revealed that their motivation for working with PALHIV was linked to the type of work they did and that they enjoyed taking care of the ailing.

Acquiring skills and experience about health matters is another attraction to this type of work.

Respondent 7 indicated that she was compelled to this type of job in home-based care as some of her family members had died from HIV/AIDS, and she felt that she could have helped them better if she had had the expertise during that period of need. That is how she ended up training in HBC. There is, however, the frustration of minimal opportunities for growth at work, especially for the research participants who have worked there for many years. The latter expressed a need to improve their skills and getting better paying jobs in future.

4.4.3 What are the coping mechanisms used by HBCGs in giving HBC to Patients living with HIV?

HBCGs experience many challenges as they provide care to their patients on a daily basis. Some of those experiences are highlighted below.

4.4.3.1 Disclosure, stigmatisation of PALHIV and confidentiality

PALHIV are facing a challenge of disclosing their status, even to the HBCGs who are caring for them, as it is often conceived as a taboo to be HIV-positive in certain communities and one runs a risk of being stigmatised.

Respondent 1 revealed that few patients reveal their status to their caregivers.

Some PALHIV cared for by research participants do not want the HBCG in uniform visiting them as they do not want neighbours to ask questions and talk about them, but the HBCGs are not allowed to see patients without wearing a uniform.

Respondent 2 shows that families visited by HBCG might be socially ostracised and stigmatised as AIDS families, especially in the cases where HBCGs wear uniforms or T-shirts with AIDS slogans.

Respondent 3 revealed that the neighbours at times interrogate the HBCGs to find out about the purpose of their visits, which most families do not appreciate as it makes them

uncomfortable. Some families go to the extent of hiding their patients from curious neighbours and community members.

Respondent 4 mentioned that the hospital sometimes allocates HBCGs to new patients whom they have to visit at designated addresses. When the HBCGs visit them, some patients claim that there is no one by that name as they do not want to be associated with HIV/AIDS. They are ashamed of HIV/AIDS and this is stressful for the HBCG as the PALHIV cannot get quality care because of this stigmatisation.

This is an indication that PALHIV and their families are subject to prejudice, discrimination and hostility related to the stigma associated with HIV. PALHIV fear being mistreated by their neighbours or community at large.

However, the HBCGs always have to allow them their right to exercise confidentiality, and provide help where they can. The HBCGs continue to give them counselling and encourage them to take treatment. It is common practice that PALHIV at times request HBCGs to keep their status a secret and at times they die without disclosing their status, which leaves the HBCG to face the questions raised by the family and she is bound to still maintain confidentiality.

Respondent 5 indicated that keeping secrets is part of my job.

Respondent 6 shows that some PALHIV neither want their families to know their diagnosis nor warn their spouses or sexual partners about their status. Such non-disclosure is the right of any person, but it disadvantages other affected people who can benefit from the information to change their behaviour and give the person support.

Respondent 7 indicated that some patients present symptoms of opportunistic infections but refuse to test for HIV, and that has to be respected as well. In the case of this study the respondents reported that PALHIV hide their status, despite the visible physical symptoms of the disease and the type of medication they take.

Respondent 8 indicated that it is easier for PALHIV to say they are suffering from TB but never from HIV/AIDS – even when they are taking ARVs. PALHIV feel ashamed and do not want to be judged, and therefore they refuse to collect treatment from the clinic or hospital for fear of being seen there by members of the community or neighbours.

This non-disclosure of certain people poses an ethical dilemma for the HBCG as it is also the right of the partner of the patient to know his/her status in order to have the option of starting treatment if they have a positive status. In this case the patient who is exercising his/her own right is violating the partner's rights. All these ethical dilemmas, together with the lack of appropriate community resources and facilities, are delaying progress in the realisation of comprehensive reproductive health.

Participant 9 reported that they counsel PALHIV to disclose their status without putting them under pressure. They rather wait for the patient to trust them enough to disclose their status. In all relationships personal or professional discrimination counteracts trust,

Respondent 10 indicated that the status of the patient was shared with the caregiver, the available support from hospitals, community and family was discussed and the patient was encouraged to use the services. Carers who are not given an honest statement by patients of their HIV status have a very chaotic caregiving experience. Research participants expressed that they feel frustrated and stressed when patients lie about their status and are in denial, as it makes it difficult for the HBCG to help them.

Respondents related how one of patients, who was bedridden when she began caring, was seeking advice on whether she could begin having sex as she was now feeling better and felt that she would have liked to have sex. However, the patient did not know whether to tell the partner or whether to just insist on a condom without disclosing her status. This shows how the issue of disclosure of one's status gives the patient an opportunity to share his or her anxieties with the HBCG and discuss sensitive issues. Had she not disclosed her status, she would not have been able to share this with her carer.

Stigmatisation is still a huge problem since it prevents open statements about HIV status. This in turn poses a problem for caregiving as there are cases where HBCGs are not even given an honest account by their patients of their status. In other cases, the HBCG is asked to keep their status confidential, which can be detrimental to the rights of other people. Universal tolerance of HIV/AIDS needs to be advocated for, through awareness programmes in an attempt to reduce stigmatisation and discrimination.

4.4.3.2 Dealing with the death of patients

Respondent 1 expressed difficulty in nursing patients whom they knew would neither fully recover nor be cured from their ailments, and would eventually die. They struggled to accept the sufferer's condition.

Respondent 2 often feel stressed, although others mentioned that they accepted the condition of their patients.

Respondent 3 experienced conflicting feelings about the death of their patients. Patience mentioned that she did not feel well when one of the patients she was nursing died; she felt stressed and could not cope.

Respondent 3 indicated that one day I went to see her and found that she had died. This never sat well with me. I treated the patient for a short period of time and felt strongly that the patient could have afforded me a chance to treat and care for her before departing, maybe she would have survived. Participants seem to feel guilty and blame herself for the death of her patient.

Respondent 4 revealed that when a patient dies, life goes on, as she felt that they were relieved from pain. All these feelings depend on various factors such as the level of attachment between the HBCG and the patient and how they deal with their emotions in relation to their work.

Respondent 5 shows that I lost an HIV positive patient who was troubled as he lost his wife to HIV and blamed himself for having infected her. He could not accept his situation; he was moody, drank a lot and was not taking treatment, but through counselling he started cooperating. He started as a bedridden patient who had various symptoms of HIV/AIDS, but eventually improved, and deteriorated later on as he stopped taking treatment. His death really affected me, but giving his family bereavement counselling and support made me stronger as I was able to deal with my grief.

Respondent 6 demonstrated a struggle with emotions when it came to dealing with the death of a patient. These emotions include a high level of guilt, self-blame and a feeling that they could have done more for the patients despite admitting that they are aware that their patients will eventually pass on.

4.4.3.3 Supportive families

Respondent 1 in this study stated that there are families that are very understanding and give full support to their patients. These supportive families get accustomed to having a patient around and want to know more about providing assistance to the patient. They share their feelings and thoughts, and the HBCGs get attached to them as they make their job easier and lighter. The HBCGs then educate and counsel them on giving care to the patient.

Respondent 2 indicated that they were well accepted by the patients' families and this gave them a platform to discuss confidential issues such as the cause of the illness, status in life as well as issues affecting the family when caring for a PALHIV. There are some families and patients who would love to see the HBCGs every day and who appreciate their help and always invite them to stay longer. This was also evident during observation when some of the patients would offer the HBCG tea and complain that their stay is too short. Some family members also write moving letters of gratitude to HBCGs.

Respondent 3 revealed that supportive environments, such as the support of their families, and services provided by non-governmental organisations, such as AIDS training and counselling centers, had success in overcoming the stigma. Counselling and health information has been reported to empower PALHIV to change their risky behaviour and adopt a healthier lifestyle, as was also found in this study.

4.4.3.4 Patient neglect or abuse by family members

Some of the families of PALHIV view HBCGs as outsiders and refuse to help them in any way. Respondent 1 viewed HBCGs as adding value to community but they are also subject to exploitation by patients and their families, as reflected in this section.

There are families who are neither there for the PALHIV nor care for their well-being and are therefore not helpful in ensuring their full recovery. In such cases patients tell the HBCG that they are often the only people to dress their wounds, they bath themselves, and their families do not assist them with anything.

This is evident when the HBCGs go for their next visit to find the patients in the same clothes, soiled and in a much worse condition, thereby increasing her workload and the time spent with the particular patient.

Respondent 2 revealed that We find patients asleep and bedridden, bath them entirely, brush their teeth, and turn them over without the assistance of the family.

4.4.4 Challenging interactions between HBCGs and patients

This section will highlight some experiences of research participants with difficult patients. Respondent 1 reported that some of the patients are extremely difficult and hard to please and they even have disagreements with them. It has been argued that PALHIV who are in denial may have avoidance tactics that may manifest in behaviour such as social withdrawal, increase in alcohol consumption, or risky behaviour.

This kind of behaviour keeps them from directly dealing with their status. Respondent 2 reported how PALHIV struggle to deal with their status and therefore overindulge in alcohol and non-nutritious food such as chocolates, sweets, and high cholesterol food. Such behaviour among PALHIV is believed to be indicative of their battling to accept this disease.

Respondent 3 revealed that find some of the patients to be very destructive as they cause conflict between them and the senior staff members by making false claims. Such false claims include complaining and mentioning to management that the HBCG had not come to see them in months, whereas the HBCG prioritises those who are badly in need of their help. HBCGs believe that they do this in the hope to cause conflict, so that the HBCG will stop seeing them. This could be because of the stigma associated with HIV/AIDS and that the neighbours are now beginning to talk, and because the patient is now feeling stronger she/he feels that the HBCG can stop assisting her/him, but does not want to say so directly.

4.1.5 Lack of knowledge

Some PALHIV absolutely refuse to take their medication, saying that they feel worse off and vomit after taking treatment. Others postpone collecting their medication from the clinic, while some miss their regular doses or postpone taking their medication. For example, one of the PALHIV told the HBCG that she was tired of taking medication and wanted to stop.

Respondent 4 indicated that there are patients who are moody and not cooperative, even if they are not very critical, and they do not have the willingness to live and help themselves. They just become hopeless and helpless and counselling by HBCGs is to no avail.

Respondent 5 reported that some patients display anger towards the HBCGs by verbally abusing them and chasing them away. Some of these patients are never satisfied with

anything given to them. Often this happens as the HBCG does not bring any food for the patient/s.

Respondent 6 highlighted that some patients at times do not like it when HBCGs use gloves, when she said: “They say we find them disgusting.” Yet HBCGs always use gloves despite such complaints.

Respondent 7 stated that when the patients are being difficult, for example when they refuse to take treatment, shout at the HBCG for no reason, or refuse to take a bath, the HBCG coaches and counsels them. In most cases they eventually change their attitude and their condition improves.

Respondent 8 mentioned that persuades and counsels patients to do what they have to do, for example take medication, by telling them of the benefits of that and how much better they will feel if they take medication consistently.

4.4 Conclusion

4.4.5 Lack of knowledge

Respondent 1 expressed difficulty in dealing with complex clinical aspects of the health of their patients such as septic wounds which included bedsores, which do not form part of their training in HBC. This makes it hard for them to give full quality care to the patient. More intensive training about the clinical aspects of care-giving can equip her better to provide a better service and, as they mentioned during the interviews, auxiliary nursing can assist in dealing with some of the clinical problems they encounter. “

PALHIV who have diabetes, some of them their feet have to be cut, and they develop bed sores, which become septic as a result of not being turned regularly.

Respondent 2 revealed that I feel inexperienced to dress such wounds and give full care to the patient, and feel they need more intensive medical attention.

Respondent 3 indicated that nurses expressed their frustration from the lack of knowledge in the management of HIV/AIDS patients, and felt that they did not receive enough training to deal with this particular aspect of their work.

Respondent 4 reported that frustration about different aspects of the caring experience is expressed, which indicates a need to close the gaps that seems to be hampering complete care of PALHIV. Continuous capacity building is vital for HBCGs to refresh their current skills and be equipped with new skills so that they can be able to provide the necessary quality care to their patients.

Where the patient requires clinical intervention they are referred by the HBCG to the hospital or clinic as they are not capacitated to deal with the intensive, clinical aspects of this work. It is important to note that courses that carers can undergo depend on availability of funds and are at times not as regular as the centre would like them to be.

4.4 Conclusion

This chapter presented and discussed the findings of this study. It gave a detailed account of the background of the centre under study, the gender-based profiles of the research participants, as well as the core services of the centre based in Ha-Mphaphuli area.

The findings highlighted the challenges that HBCGs face on a daily basis as they give support to PALHIV which encompasses the rewarding experiences as well as difficult ones that require intervention of the centre supervisor. Coping mechanisms adopted by HBCGs as a way of coping with the emotional and physical strain of the job are also mentioned. It is noted that there is support from the centre although it is not always seen to be sufficient. It is clearly articulated that care giving is rewarding, yet very emotional for the HBCGs as they experienced negative and positive emotions.

The following chapter concludes this study. It further gives recommendations based on the findings of the study which are directed to the HBCC in Vhembe district and government departments involved with HBC.

5.1 Introduction

In this chapter the researcher will present this study's conclusions and recommendations for interventions and future research. This study has shed some light to better understand the strategies that HBCGs in a HBCC use to deal with the daily psychological and social challenges they experience during their caregiving, and the type of social support available to HBCGs from the HBCC to assist them in coping with their work. The study has further identified possible remedies to some of the challenges experienced by HBCGs, which could complement the already existing support available at the centre.

5.2 Major Findings of the study

- In this section the following conclusions were drawn, based on the major findings categorized into three main themes, namely research participants, psychological and social challenges faced by HBCCs, coping mechanisms, and support provided for HBCGs.
- The findings showed that the HBCGs did not feel safe as they walked in the streets of Vhembe district to visit their patients, a critical factor that needs more attention from the senior staff members at the centre. The centre could buy the HBCGs safety gear and if there is funding, could send them for self-defence classes.
- The findings revealed signs of slowing the provision of care to PALHIV. Most PALHIV and their families still bear the abuse and stigmatisation by their community associated with HIV/AIDS, especially in cases where the HBCGs wear uniforms. Disclosure is key to good relations between the HBCG and the PALHIV and better care that may impact on the general well-being of the patient.

CHAPTER 5: FINDINGS, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

In this chapter the researcher will present this study's conclusion and recommendations for interventions and future research. This study has shed some light to better understand the strategies that HBCGs in a HBCC use to deal with the daily psychological and social challenges they experience during their caregiving, and the type of social support available to HBCGs from the HBCC to assist them in coping with their work. The study has further identified possible remedies to some of the challenges experienced by HBCGs, which could complement the already existing support available at the centre.

5.2 Major findings of the study

- In this section the following conclusions were drawn, based on the major findings categorised into these main themes, namely research participants, psychological and social challenges faced by HBGCs, coping mechanisms, and support provided for HBCGs.
- The findings showed that the HBCGs did not feel safe as they walked in the streets of Vhembe district to visit their patients a critical factor that needs more attention from the senior staff members at the centre. The centre could buy the HBCGs safety sprays and if there is funding, could send them for self-defence classes.
- The findings revealed stigma as slowing the provision of care to PALHIV. Most PALHIV and their families still fear the abuse and stigmatisation by their community associated with HIV/AIDS, especially in cases where the HBCGs wear uniforms. Disclosure is key to good relations between the HBCG and the PALHIV and better care that may impact on the general well-being of the patient,

- thereby improving the general health status of the patient. PALHIV should be encouraged to share their status so that they can be cared for effectively, and so that HBCGs can also ensure protection of both the patient and themselves.
- The findings revealed that poverty is one of the socio-economic factors that make the caring experience difficult and thus impedes the overall recovery of the patients, as they cannot take their medication without eating. Although the HBCGs at times bring them food, this is not sufficient to cater for all their needs, especially in cases where the social grant has been stopped.
- The HBCGs in general contribute substantially to the health of fellow community members which indirectly translates as savings for the national health budget, as they are not well remunerated – an essential economic factor raised by all the research participants in this study.
- The findings in this study further highlighted poor communication between the HBCGs and the employer, creating mixed emotions, confusion and twisted information, and also a feeling that there was favouritism and to a certain extent lack of respect between senior staff members and HBCGs. There was confusion about opportunities for growth, especially with regard to training and to a certain extent an insinuation of nepotism.

5.3 Conclusion

The above research findings emanate from a qualitative study in which the experiences of volunteers involved in home-based care of people living with HIV/AIDS in the Vhembe District were investigated. On the basis of these research findings and the literature control the following conclusions can be drawn:

- There appears to be a lack of coordination, cooperation and collaboration in the field of HIV/AIDS service delivery.

- Volunteers practicing home-based care with people living with HIV/AIDS carry an insurmountable burden of being expected to provide a service with very limited resources and in most instances finding themselves utilizing their own resources because of the client realities they are faced with.
- Home-based care helps the helpless, the abandoned, the vulnerable and the marginalised in a way that improves their quality of life to the extent that others recover from their illnesses and become active members of their families again.
- Lack of resources and infrastructure make life very difficult for both volunteers and those they serve and severely impede the quality of home-based care service rendering.
- The good work done by volunteers is not tangibly recognized by government.
- In this final chapter, the researcher gave a brief summary of the research methodology as applied in the second chapter. This was followed by the conclusions and recommendations concerning the qualitative methodology that was used in the study. The researcher then presented the main research findings based on the experiences of volunteers involved in home-based care of people living with HIV/AIDS. Based on those findings, conclusions were drawn which were followed by recommendations on the study as a whole. The aforementioned findings support the vital role fulfilled by volunteers in home-based care of PLWHA.

5.4 Recommendation

- The government, the private sector and NGOs pledge financial and material resources every year to fight the scourge of HIV/AIDS but these resources do not seem to reach those who need them most. It is recommended that government; the private sector and NGOs should be transparent in publicising their policies, procedures and criteria for accessing their financial and material resources so that even those in the remotest rural areas can access these resources. It is further recommended that these policies, procedures and criteria should be user-friendly.

- The prevention, care and support programmes of HIV/AIDS should follow the continuum of care model where the link between the home, the community and the formal government services is established. This model is in the policies of government particularly Departments of Health and Social development but practically, there is nothing happening. The government should harness resources both financial and human to implement the continuum of care model.
- It is recommended that the coordination and management of HIV/AIDS programmes receive urgent attention in order to deal with fragmentation experienced in this service delivery area. It is recommended that District AIDS Councils (DACs) at the district level and Local AIDS Councils (LACs) at local municipal levels be established in the same format as the Provincial AIDS Councils.
- The Department of Health should create a structure within the District particularly at local municipal level, that will be populated with competent people to handle HIV/AIDS programmes. To employ just one HIV/AIDS Coordinator or HIV/AIDS and Communicable diseases Coordinator at district level is not enough, in fact, that is why PLWHA and their families suffer the way that was exposed by volunteers in this study. This structure should be designed in such a way that it accommodates and recognises volunteers because volunteers in the field of HIV/AIDS and home based care in particular are an indispensable human resource. These volunteers should be supplied with the necessities of being an HIV/AIDS volunteer like food supplements and care kits.
- The use of free volunteers in HIV/AIDS programmes especially home-based care is not sustainable. The government cannot discharge obviously terribly sick people from health institutions to be cared for at home by 'faceless' people who are not known and do not account to health authorities and whose competency and proficiency in health care has not been certified or accredited. Potentially unregulated health care can be a violation of the human rights of PLWHA because

health is a constitutional mandate and there is an obligation to provide health care services to South Africans. This responsibility cannot be delegated to free volunteers who are not obliged or compelled to visit and care for any sick person. The government appears to be capitalizing on the vulnerability of the unemployed and their generosity of spirit to provide home-based care. It is recommended that government employ appropriately trained volunteers as fieldworkers or community health workers to address the magnitude of the HIV/AIDS pandemic.

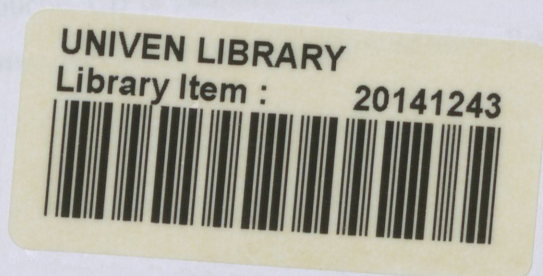
- The fieldworkers/community health workers recommended above should also be charged with HIV/AIDS community education/awareness.
- It is recommended that further research be conducted in the following areas: the experiences of those receiving care and support from volunteers; the challenges faced by home-based care service providers especially CBOs and NGOs in training and retaining volunteers; the accreditation of training for volunteers; the investigation of a sustainable system of volunteering in home-based care and the development of appropriate policies and guidelines for volunteers in home-based care.
- Lack of or minimal support from the senior staff members can cause the HBCGs to suffer emotional fatigue to the extent that they are unable to render quality care for PALHIV. HBCGs also need to support each other and make their voices heard at decision-making level concerning the allocation of resources and manpower and opportunities for growth (Ehlers 2006). They can do so by selecting a spokesperson who will communicate their interests and complaints to management to avoid confrontations in the presence of everyone.
- HBCGs need to be supported with adequate supplies and infrastructure, relevant information and guidelines to be able to carry out their duties to full capacity. The HBCC in Ha-Tshivhase can try to have team building expeditions, annually if possible, to review and recreate synergy.

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- Support groups need to be formalised with time allocation periodically where HBCGs can share their caring experiences with each other. Peer networks can also help; HBCGs from the HBCC in Ha-Mphaphuli could interact with others in the same field to share their caring experiences.

5.5 Recommendations for future research

- It is recommended that further research be undertaken to investigate coping mechanisms of HBCGs who care for PALHIV in various HBC programmes in Ha-Mphaphuli. Such a study will enable the researcher to draw a more generalised conclusion about HBCGs in Ha-Mphaphuli and can suggest a community-based approach to support the HBCGs. This would therefore address the first limitation of this study.
- More research should be considered on the impact of the withdrawal of social grants received by PALHIV on their recovery and survival. This kind of research will enable HBCGs to have a better understanding of what leads to withdrawal of social grants and they will be able to make informed choices on how to ensure that grants are not stopped, thereby improving the financial capacity and well-being of their patients and enhancing the quality of their care.



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Section A: Biographical Information

INTERNET REFERENCES

Gender Distribution of the respondents

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Occupational status

House Wife	
Small scale business	
Employed	
Pensioner	
School dropout	

Level of education

Never attended school	
Primary school	
secondary school	
Tertiary school	

Marital status

Married	
Single	
Divorced	
Widow	
widower	

APPENDIX A: QUESTIONNAIRE

Section A: Biographical Information

Gender Distribution of the respondents

Male	
Female	

Occupational status

House Wife	
Small scale business	
Employed	
Pensioner	
School dropout	

Level of education

Never attended school	
Primary school	
Secondary school	
Tertiary school	

Marital status

Married	
Single	
Divorced	
Widow	
widower	

SECTION B:

Challenges and managing mechanisms of Home-Based caregivers for patients living with HIV/AIDS

Please complete all questions Mark with an “x” Mark from Strongly Agree to Strongly Disagree

Statement	Strongly agree	agree	uncertain	disagree	Strongly disagree
There is a stigma attached to the HIV/AIDS suffer					
The health care gives helping patient					
Home based care givers are well funded					
The Government fully supported the Home based care givers.					
Patient respect the role of home based care givers					
Home based care givers access funds easily for their programmes to function.					
Home based care has a future.					
Lack of financial management skills render the Home based care dysfunctional.					

The management committee member has the necessary management skills.					
There are enough gloves to handle the HIV/AIDS patient					
The management of HIV/AIDS is hampered by lack of ARV.					
The current management is winning the war towards HIV/AIDS.					
The home based care givers have the necessary skills to manage HIV/AIDS.					
The management of HIV/AIDS is getting support from the media.					

APPENDIX B: INTERVIEW

What type of emotion do you experience when you are struggling to deal with challenges?

.....
.....
.....

What is the bereavement counselling and support to family members?

.....
.....
.....

What is motivation for care giving?

.....
.....
.....

What is disclosure, stigmatization of PALHIV and confidentiality?

.....
.....
.....

THANK YOU FOR YOUR PARTICIPATION